RECONCEPTUALIZING BEHAVIOR OUTBURSTS IN ASD: THE ROLE OF ANXIETY

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ABSTRACT

Katerina M. Dudley: Reconceptualizing Behavior Outbursts in ASD: The Role of Anxiety
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Behavior outbursts (e.g., tantrums, aggression, self-injury) are the leading cause of psychiatric hospitalizations for those with autism spectrum disorder (ASD) and relate to worse individual and family quality of life (QOL). Thus, the clinical significance and need for treatment of behavior outbursts is clear. Despite significant changes in the ASD population in the last several decades (i.e., increase of psychiatric comorbidities such as anxiety, less cognitive impairment), our conceptualization and treatment of behavior outbursts as an associated feature of ASD have experienced little change. The continued focus on behavior outbursts in ASD as an indication of an externalizing behavioral disorder has not examined the potential for internal mechanisms (e.g., anxiety) that could be driving their occurrences. Thus, the present study aimed to examine the role of anxiety as a mechanism through which behavior outbursts occur and its impact on individual and family outcomes in an intellectually diverse adult sample. Results indicated that anxiety played a key role in directly and indirectly increasing behavior outbursts and family burden, and in indirectly decreasing QOL for adults with ASD. Notably, the importance of anxiety was supported for both those with poor and good communication abilities, suggesting its significance for adults with ASD across the intellectual spectrum. The current findings clearly document the need to assess for and treat anxiety as a potential means to improve behavior outbursts, QOL, and family burden for adults with ASD with and without intellectual impairments.

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ASD	Autism Spectrum Disorder
QOL	Quality of life
ID	Intellectual Disability
CDC	Centers for Disease Control
DSM	Diagnostic Statistical Manual
ABA	Applied Behavior Analysis

INTRODUCTION

As defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), Autism Spectrum Disorder (ASD) is characterized by deficits in social communication and includes the presence of restricted and repetitive behaviors and interests (RRBIs) (American Psychiatric Association, 2013). These two areas are critical to the diagnosis of ASD and frame our conceptualization of this disorder. However, in addition to social deficits and RRBIs, there are several associated features of the disorder, with behavior outbursts (e.g., tantrums/meltdowns, aggression, self-injury) being one of the most frequently mentioned. In Leo Kanner's seminal paper first conceptualizing ASD, he described destructive tantrums and breakdowns that were difficult to stop (Kanner, 1943). Recent research has continued to support behavior outbursts as an associated feature of ASD, with studies indicating that a majority of individuals on the autism spectrum are identified to have these issues (e.g., Jang, Dixon, Tarbox, & Granpeesheh, 2011; Reiss, 1988). Importantly, behavior outbursts are a leading cause of psychiatric hospitalizations across the ASD spectrum (Siegel & Gabriels, 2014) and have been shown to relate to worse quality of life (QOL) for the individual with ASD and for their family (e.g., Estes et al., 2009; Lecavalier, Leone, & Wiltz, 2006), emphasizing their importance and need for treatment.

With evidence for an impact on QOL and a leading cause of psychiatric hospitalizations, researchers and clinicians have sought to better understand behavior outbursts. However, the field has made relatively little change in their conceptualization of behavior outbursts in decades, despite the ASD population changing significantly during this time (Baio, Wiggins, Christensen, & Al., 2018). Previously, autism was reported to occur in 1 in 2,500 individuals and was thought

to only impact those who were considered intellectually impaired (Fombonne, 2005; Lotter, 1966). In contrast, ASD currently occurs in 1 in 59 individuals and the fastest growing subgroup is those with average to above average IQs (Baio et al., 2018). For instance, the most recent CDC report indicates that 44% of individuals with ASD have average to above average IQs and only 30% have an intellectual disability (ID) (Baio et al., 2018). In addition to a change in the prevalence and level of intellectual impairment associated with this population, the fact that ASD has always been considered a childhood disorder has impacted our framing of the disorder and treatment approaches (Klinger & Dudley, 2019). However, millions of adults have a diagnosis of ASD and over 50,000 individuals with ASD enter adulthood each year (Nightingale, 2012; Shattuck et al., 2012). Lastly, previous DSM versions did not allow for the diagnosis of ASD to occur with other psychiatric diagnoses (e.g., ASD + internalizing disorders, attention deficit hyperactivity disorder). Thus, assessing and treating core ASD symptoms *and* other psychiatric concerns were not part of the ASD field's previous framework. With the advent of DSM-5, the field has recognized that ASD can co-occur with other psychiatric diagnoses. As such, within the last decade studies have found that over 70% of ASD children meet criteria for a psychiatric diagnosis (Simonoff et al., 2008). As a whole, the ASD population that researchers and clinicians are currently seeing tends to be older, less cognitively impaired, and exhibit comorbid psychiatric diagnoses compared to previous generations. Even with these significant changes in the current ASD population, behavior outbursts remain a common referral concern for both children and adults with ASD (Mazefsky, Pelphrey, & Dahl, 2012; Samson, Hardan, Podell, Phillips, & Gross, 2014).

Historically, behavior outbursts in those with ASD have generally been treated using an applied behavior analysis (ABA) approach or through discipline strategies (e.g., Eyberg, 1988; Patterson, 1982; Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; McGee & McCoy, 1981;

Odom & Strain, 1986; Schreibman, 2000). These behaviorist approaches are founded upon the experimental analysis of behavior, which seeks to understand the environmental events that influence and affect behavior. As such, clinicians using a behavioral framework aim to examine and change the *external* factors prior to (i.e., antecedent) and after (i.e., consequence) an event to impact the likelihood that a behavior will occur. Although ABA was originally used for individuals with below average IQs or very young children, it continues to be used with those who have average to above average IQs and those in adolescence and adulthood, despite recent pushback from self-advocates with ASD indicating many of them consider this treatment "harmful" due to its one-size-fits-all approach (Devita-Raeburn, 2016). Similarly, behavioral discipline strategies such as punishment are often used to treat behavior outbursts, especially when they are interpreted as purposeful and noncompliant (Eyberg, 1988; Patterson, 1982). Both ABA approaches and discipline strategies have clear evidence for their treatment effectiveness in ASD (see Klinger & Dudley, 2019, for a review), however, these approaches generally ignore the internal factors, such as anxiety, through which behavior outbursts could be occurring (e.g., antecedent→*anxiety increase*→behavior outburst→consequence). For instance, what if a behavior outburst (e.g., aggression, tantrum) is a product of an anxiety attack, rather than due to noncompliance. This shift in inclusion of *internal* changes impacting an event sequence would allow for the targeting of internal factors, rather than just the external circumstances surrounding an event.

Little attention has been paid to whether internalizing factors, including anxiety, could drive some behavioral outbursts. Similar to behavior outbursts, anxiety occurs in a large percentage of the ASD population (Kent & Simonoff, 2017) and has been shown to impact QOL (van Steensel, Bogels, & Dirksen, 2012). Although both behavior outbursts and anxiety appear to have significant influences on QOL outcomes (Chadwick, Walker, Bernard, & Taylor, 2000;

Estes et al., 2009; Kerns et al., 2015; Lecavalier et al., 2006), and it is plausible they could relate to one another, no studies have been conducted assessing theoretically-driven models that test the potential relationships between these domains. A reconceptualization of behavioral outbursts as being related to underlying anxiety would recommend a shift in treatment approaches which may prove more effective at long-term treatment of behavior outbursts (e.g., including intervention models that target internalizing symptoms). In the last decade, the ASD field has become more open to cognitive-behavioral treatment (CBT) approaches with the increase of those with average to above average IQs, but is still far behind the general Psychology field in terms of its understanding of behavior outcomes that could be addressed through CBT and other anxiety-reduction approaches (Klinger & Dudley, 2019).

A better understanding of behavior outbursts in ASD, including the potential impact of anxiety as a mechanism through which outbursts occur, is necessary to guide the treatment field. In order to bridge this gap in the research, a review of the ASD literature on behavior outbursts, anxiety, individual and family QOL, and the emotion regulation framework is necessary to create and test theoretical models mapping relationships between these constructs.

Behavior Outbursts in ASD

Behavior outbursts are often characterized as tantrums, meltdowns, aggression, self-injury, and property damage (e.g., throwing objects, punching walls) (e.g., Blacher & McIntyre, 2006; Hartley et al., 2008; Lerner, Haque, Northrup, Lawer, & Bursztajn, 2012; McCarthy et al., 2010). These behaviors are referred to differently depending on the literature reviewed, but most frequently are considered within the classes of "problem behaviors," "maladaptive behaviors," and "challenging behaviors." There are very few distinctions between these labels and all tend to provide similar examples in their definitions. Regardless of their reference term, these types of behavior outbursts are extremely common for individuals with ASD. For instance, one study that

included children across the IQ spectrum found that 87% of their sample was reported to exhibit behaviors aligned with these definitions (Murphy, Healy, & Leader, 2009). Of all the types of behavior outbursts, tantrums and aggression are most frequently targeted by interventions for children with ASD (Bolte & Diehl, 2013; Horner, Carr, Strain, Todd, & Reed, 2002).

Not only has research consistently found that behavior outbursts are extremely common for those on the autism spectrum, the literature has also indicated that they occur more frequently compared to individuals with typical development and compared to those with other disorders and disabilities (e.g., Bradley, Summers, Wood, & Bryson, 2004; Matson, Wilkins, & Macken, 2008; McCarthy et al., 2010; McClintock, Hall, & Oliver, 2003; Richards, Oliver, Nelson, & Moss, 2012). Additionally, research has shown that behavior outbursts last for longer periods of time for those with ASD compared to peers with typical development (Jahromi, Meek, & Ober-reynolds, 2012), suggesting that it is more difficult for those with ASD to re-regulate themselves after having a behavior outburst.

Research has also compared these behaviors across diagnoses that are associated with Intellectual Disability (ID) (e.g., ASD, Down Syndrome, Fragile X, Prader-Willi Syndrome, Williams Syndrome). Across various studies, results indicate that individuals with ASD and comorbid ID demonstrate more behavior outbursts compared to those with ID without ASD (Bradley et al., 2004; Matson et al., 2008; McCarthy et al., 2010; McClintock et al., 2003). For instance, one study found that adults with ASD and comorbid ID were four times more likely to exhibit challenging behaviors compared to adults with only ID (McCarthy et al., 2010). Other studies have found that specific aspects of these behaviors are more common in ASD compared to other types of intellectual disabilities. A meta-analysis of maladaptive behaviors in children and adults with different types of IDs found that aggression, disruptive behavior, and self-injury were more common for those with ASD compared to other diagnoses (McClintock et al., 2003).

Similarly, another study found that children with ASD had significantly higher levels of self-injurious behavior (50% of ASD sample) compared to children with Down Syndrome (19% of DS sample) (Richards et al., 2012). These results suggest that behavior outbursts are not simply a product of intellectual functioning, but that they are uniquely associated with ASD in a way not seen in other populations.

Predictors of Behavior Outbursts

In order to better understand behavior outbursts, potential predictors of these behaviors have been evaluated. Although ASD diagnosis has been consistently found to predict behavior outbursts (e.g., McCarthy et al., 2010; McClintock et al., 2003), there is less consensus regarding the impact of ASD symptom severity. Some studies have found that ASD symptom severity does not predict challenging behaviors, suggesting that these behaviors occur equally across severity levels of the autism spectrum (Hartley et al., 2008; Mctiernan, Leader, Healy, & Mannion, 2011; Murphy et al., 2009). In comparison, other studies have indicated that ASD symptom severity predicts behavior outbursts, with more severe ASD symptoms relating positively to the number and intensity of challenging behaviors (Jang et al., 2011; Matson et al., 2008). In addition, although less frequently studied, some researchers have noted that certain aspects of ASD symptoms predict behavior outbursts more than others. For instance, Maddox and colleagues (2017) found that increased insistence on sameness (i.e., narrow interests, rigid routines, rituals, wanting things to occur the same way) as measured by the Repetitive Behaviors Scale—Revised (RBS-R) (Bodfish, Symons, Parker, & Lewis, 2000) significantly predicted higher levels of challenging behaviors in youth with ASD.

In addition to ASD symptom severity, the relationship between intellectual functioning and behavior outbursts has also been frequently evaluated. Overall, the majority of the results indicate that IQ has a negative relationship with behavior outbursts, with individuals with ASD

with lower intellectual functioning displaying more problem behaviors (Mctiernan et al., 2011; Murphy et al., 2009). More specifically, studies have found that those with ASD with low IQs tend to display higher frequency and higher intensity of self-injurious behaviors and higher frequency of aggressive behaviors compared to those with higher IQs (Mctiernan et al., 2011). In further support of IQ differences in behavior outbursts, longitudinal studies have documented that not only do individuals with ASD with lower IQs demonstrate more maladaptive behaviors compared to those with average to above average IQs, but these behaviors also improve less across time (Shattuck et al., 2007; Taylor & Seltzer, 2010). However, it is noteworthy that even though individuals with average to above average IQs tend to exhibit fewer behavioral outbursts, they do exhibit these behaviors (Jang et al., 2011; Maddox et al., 2017). Theorists have suggested that the expression of these behaviors may be a communication method (Hartley et al., 2008), as communication impairments (e.g., verbal, non-verbal) are considered a core symptom of ASD across the IQ spectrum (American Psychiatric Association, 2013). That is, behavioral outbursts may be a way of communicating distress for those with ASD across the intellectual spectrum.

Behavior Outbursts Across Development

Developmentally, research has found that age is a predictor of maladaptive behaviors, with the majority of research indicating that older individuals with ASD demonstrate fewer maladaptive behaviors than younger individuals with ASD (Gray et al., 2012; Shattuck et al., 2007; Taylor & Seltzer, 2010). For instance, Shattuck and colleagues (2007) found that adults (age 31 and up) with ASD had fewer maladaptive behaviors compared to adolescents and young adults with ASD. In contrast, Taylor and Seltzer (2010) found in their longitudinal study that although maladaptive behaviors improved throughout childhood and adolescence, they significantly slowed in their improvement after high school exit. Together, these results suggest that there may be certain developmental periods when these behaviors are more likely to

improve, and other periods in which improvement may slow or even stop. However, even in instances in which improvements across time are evidenced, these behaviors have been found to remain at clinically elevated levels in adulthood (Gray et al., 2012). This suggests that, despite potential improvements in behavior outbursts, they continue to remain a major issue for individuals with ASD across development (i.e., evidence for continuity and change).

Summary of ASD Behavior Outburst Literature

Together, it appears that behavior outbursts are more prevalent in ASD, even compared to those with other disabilities associated with ID. Although there is less consensus, ASD symptom severity, and more specifically insistence on sameness behaviors, have been found to predict behavior outbursts. The most consistent predictor of behavior outbursts is intellectual functioning, with individuals with lower IQs displaying more of these behaviors. However, there is evidence that individuals with ASD across the IQ spectrum demonstrate a higher prevalence of these behaviors than expected. Similarly, adults with ASD tend to have fewer instances of behavior outbursts compared to younger individuals, but that these behaviors are still higher than expected compared to non-ASD individuals. Thus, there is evidence that behavior outbursts occur for individuals with ASD throughout development.

Anxiety in ASD

As anxiety is not considered a core symptom of ASD, it has received less attention compared to the primary deficit domains related to the diagnosis (i.e., social communication, RRBIs) (American Psychiatric Association, 2013). However, research examining the association between anxiety and ASD has substantially increased in the last decade with the rise in the number of individuals with ASD with average to above average IQs. From these investigations, there is growing consensus that individuals on the autism spectrum experience significant levels of anxiety symptoms, above and beyond non-ASD populations (e.g., Kent & Simonoff, 2017;

Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Sukhodolsky et al., 2008; van Steensel, Bögels, & Perrin, 2011; White, Oswald, Ollendick, & Scahill, 2009).

Rates and Subtypes of Anxiety

Overall prevalence estimates of anxiety disorders for those with ASD range from 11% to 84%, with most studies reporting a prevalence rate of approximately 40-50% (Kent & Simonoff, 2017; Kim et al., 2000; van Steensel et al., 2011; White, Oswald, Ollendick, & Scahill, 2009). This anxiety prevalence rate is notably higher than the 5-10% prevalence rates of anxiety disorders seen in the general population (Kent & Simonoff, 2017; Kim et al., 2000; White et al., 2009). In addition to documenting a clinically significant presence of anxiety for many individuals with ASD, studies have also sought to identify the different subtypes of anxiety seen in this population, with some studies indicating that up to 87% of children with ASD with anxiety elevations have two or more comorbid anxiety disorders (Renno & Wood, 2013). It appears, then, that individuals on the autism spectrum are often not affected by a single type of anxiety, but frequently exhibit symptoms mapping onto to several classifications of anxiety disorders. Although it is difficult to differentiate between the various anxiety subtypes for those with ASD, specific phobia is frequently cited as the most common comorbid anxiety disorder (approximately 30% meeting DSM criteria) (e.g., Morrow Kerns et al., 2014; van Steensel et al., 2011). There is less consensus regarding the frequency of other anxiety disorders. However, generalized anxiety disorder (GAD), obsessive compulsive disorder (OCD), social anxiety disorder/social phobia, and separation anxiety disorder are regularly noted as the next most commonly provided anxiety disorders (Kent & Simonoff, 2017; van Steensel et al., 2011; White et al., 2009).

Typical and Atypical Presentations of Anxiety

With certain anxiety diagnoses more frequently identified, researchers have sought to better understand the manifestations of anxiety and how they may be distinctive from those seen in other populations. For instance, Morrow Kerns and colleagues (2014) examined anxiety presentations in children and adolescents with ASD (i.e., ages 7-17, IQs greater than 60) with the goal of determining whether a participant's anxiety was considered consistent (i.e., "traditional") or inconsistent (i.e., "atypical") with diagnostic and statistical manual (DSM) descriptions of anxiety disorders. Examples of atypical anxiety that are not regularly seen in the general population are fears of loud sounds, unusual phobias (e.g., intense fear of toilets, beards, mechanical objects, changes in environment or schedule), social phobia without concern of rejection, and rigid behavior related to rule-governed preferences (e.g., only eating food of one color, verbal rituals). Study results indicated that 17% of participants presented with traditional anxiety, 15% presented with atypical anxiety, and 31% of the sample presented with both typical and atypical forms of anxiety (Morrow Kerns et al., 2014). Interestingly, language ability, anxious cognitions, and hypersensitivity, but not ASD symptoms, predicted traditional anxiety. In comparison, ASD symptoms and traditional anxiety predicted atypical anxiety (Morrow Kerns et al., 2014). These results suggest that individuals with ASD experience manifestations of anxiety that are similar to those of the general population, but they also experience atypical symptoms of anxiety that are not often seen in the general population and are directly associated with the hallmark features of ASD (i.e., social communication, RRBIs). In line with this, Leo Kanner, who diagnosed the first cases of autism, noted these types of atypical anxiety features in his seminal paper describing autism in the early 1940s (Kanner, 1943), suggesting that, although rarely addressed in the literature, an atypical anxiety presentation has be associated with this diagnosis since its original conceptualization.

Predictors of Anxiety

In addition to examining anxiety presentations in ASD, researchers have also sought to understand the predictors of anxiety. For instance, IQ and language level have been evaluated as potential predictors of anxiety. The majority of the research suggests that greater levels of anxiety are seen in children and adolescents with ASD who have average to above average IQs and functional language abilities (Dubin, Lieberman-Betz, & Michele Lease, 2015; Gotham, Brunwasser, & Lord, 2015; Hallett, Lecavalier, Sukhodolsky, & Cipriano, 2013; Kerns et al., 2015; Morrow Kerns et al., 2014), perhaps because of greater insight into their struggles with social understanding and ability to self-report on the anxiety symptoms that they experience. Although those with ASD with average to above average IQs may exhibit more anxiety symptoms compared to those with lower IQs and lower language abilities, several studies still suggest that anxiety occurs (although potentially to different extents) across the autism spectrum (Eussen et al., 2013; Strang et al., 2012). In support of this, Bradley and colleagues (2004) examined anxiety in children with ASD with comorbid ID compared to those with severe ID without ASD; significantly more of the ASD with comorbid ID sample met criteria for clinically significant anxiety symptoms compared to those with ID only. Other studies have found that IQ may reflect different relationships depending on the subtype of anxiety. For instance, Sukhodolsky and colleagues (2008) found that higher intellectual capabilities were only associated with GAD, separation anxiety disorder, and panic-related worries, but specific phobias and social phobias were equally common across low and high IQ participants (Sukhodolsky et al., 2008).

Another common predictor of anxiety examined in the literature is ASD symptom severity. Some studies have indicated that there is no relationship between ASD symptom severity and anxiety symptoms (e.g., Renno & Wood, 2013). However, the majority of studies

suggest that ASD symptoms, specifically those related to the RRBI domain of the diagnosis, positively relate to anxiety symptoms as measured by both parent- and self-report (Joyce, Honey, Leekam, Barrett, & Rodgers, 2017; Magiati et al., 2016; Rodgers, Glod, Connolly, & McConachie, 2012; Sukhodolsky et al., 2008; Teh, Chan, Tan, & Magiati, 2017; Wigham, Rodgers, South, McConachie, & Freeston, 2015). This clear relationship between RRBIs and anxiety has not been found in other populations prone to anxiety who have similar developmental delays (i.e., Williams Syndrome), suggesting it may play an important and unique role in anxiety for those with ASD (Rodgers, Riby, Janes, Connolly, & Mcconachie, 2012). Moreover, some researchers have posited that RRBIs play a role in the development and maintenance of anxiety not only in predicting the presence of elevated anxiety, but that RRBIs may also be used as a coping mechanism to reduce anxiety (Joosten, Bundy, & Einfeld, 2009; Rodgers, Glod, Connolly, & Mcconachie, 2012; Rodgers, Riby, et al., 2012; Spiker, Lin, Dyke, & Wood, 2012). These researchers hypothesize that RRBIs may serve a similar function as the compulsions seen in OCD, as they share parallel features in their repetitiveness and rigidity in routine (Rodgers, Riby, et al., 2012; Spiker et al., 2012). For instance, an individual with ASD could use repetitive or ritualistic behaviors to cope with anxiety, just as an individual with OCD may use compulsions to cope with obsessive thoughts.

With a consistent relationship evidenced between RRBI symptoms and anxiety, studies have begun to examine potential aspects of RRBIs that may be playing a role in predicting anxiety symptoms. The majority of this research has focused on insistence on sameness and intolerance of uncertainty. Overall, the insistence on sameness aspect of RRBIs has garnered the most support in its relationship to anxiety (Rodgers, Glod, Connolly, & McConachie, 2012; Uljarević, Richdale, Evans, Cai, & Leekam, 2017). For instance, Lidstone and colleagues (2014) found that anxiety was significantly and selectively associated with insistence on sameness

behaviors, and other studies have also supported this relationship (Rodgers, Glod, Connolly, & McConachie, 2012; Uljarević et al., 2017).

In addition, an insistence on sameness related construct that has been investigated in its association to anxiety in non-ASD samples (and more recently in ASD-samples) is referred to as "intolerance of uncertainty," (IU) which is defined as an individual's negative perception of situations in which there is a high level of uncertainty (e.g., in outcome, in next steps) (Dugas, Gagnon, Fabien, Ladouceur, & Freeston, 1998). At its core, IU relates to insistence on sameness behaviors in that if an individual has poor abilities to tolerate uncertainty, they tend to desire to keep things in their life the same. In non-ASD anxiety samples, IU has been found to serve as a key feature in predicting anxiety disorders, with results consistently indicating significant positive relationships between higher IU and higher levels of anxiety and worry (e.g., Buhr & Dugas, 2009; Carleton et al., 2012; Yook, Kim, Suh, & Lee, 2010). While little research has been conducted on the intolerance of uncertainty in ASD, recent research suggests that it may be related to anxiety in ASD (Boulter, Freeston, South, & Rodgers, 2014) and may play a role in treatment response, with children with ASD with higher pre-intervention levels of IU showing less CBT-based treatment change (Keefer et al., 2017).

Anxiety across Development

Although there is strong evidence supporting the presence of significant anxiety symptoms for individuals with ASD in toddlerhood (e.g., Ben-Sasson et al., 2008; Green et al., 2012), early to middle childhood (e.g., Baker et al., 2008; Kim et al., 2000; White et al., 2009), and adolescence and early adulthood (e.g., Joyce et al., 2017; Uljarević et al., 2017), there is scarce information investigating anxiety in in middle to late adulthood. In addition, less research has been conducted assessing changes in anxiety symptoms throughout development for those on the autism spectrum. However, it appears that anxiety remains a problem throughout

development, with some increases and decreases across the lifespan. For instance, Davis and colleagues (2011) investigated anxiety symptoms in a cross-sectional sample of 131 individuals diagnosed with autism from infancy to adulthood (age range 17 months-65 years); results indicated that anxiety increased from toddlerhood to childhood, decreased from childhood to young adulthood, and increased again from young adulthood to older adulthood. Another longitudinal study investigating anxiety in those with ASD ($N = 165$, age range 6-24 years) indicated that adolescence was a specific developmental period in which females may see increases in anxiety; even though males had higher levels of anxiety in middle childhood, by early adulthood, there were no gender differences in anxiety symptoms (Gotham et al., 2015). Throughout this longitudinal study, individuals with ASD had higher levels of anxiety than those with other forms of developmental delay, suggesting anxiety remains a problem throughout childhood and early adulthood for those on the autism spectrum compared to those with similar intellectual styles (Gotham et al., 2015).

Treatment of Anxiety

With high anxiety prevalence rates evidenced across development, clinicians and researchers have attempted to treat this associated feature of ASD. In the general population, the gold standard method for treating anxiety is cognitive-behavioral therapy (CBT) (Beck, 2011). In CBT, psychoeducation, self-monitoring of symptoms, thought identification and challenging, and coping strategies are often employed to target symptoms (see Beck, 2011, for a review). As noted, previous conceptualizations and treatment frameworks of ASD were often founded on targeting core ASD symptoms in more impaired individuals (often early in development) with significant cognitive delays. Thus, CBT approaches were not previously conceptualized as treatment options for this population. However, as the rates of those with ASD who have average to above average IQs have increased (Baio et al., 2018), so, too, has the openness to CBT-based

treatments. Although some adaptations are often employed (e.g., emotion regulation training, more cognitively concrete and structured approach, involving caregivers, greater use of visuals and structured worksheets) (see Klinger & Dudley, 2019, for a review), various studies have demonstrated medium to large effect size decreases in anxiety post-CBT (Reaven, Blakeley-Smith, Culhane-Shelburne, & Hepburn, 2012; Reaven, Blakeley-Smith, Nichols, & Hepburn, 2011; Scarpa & Reyes, 2011; Wood et al., 2015). Results from these studies indicate that anxiety can be effectively targeted through CBT for those with ASD with average to above average IQs. As such, CBT is now considered an evidence-based practice for this population (Lang, Regester, Lauderdale, Ashbaugh, & Haring, 2010; Wong et al., 2015). Importantly, research teams (e.g., Judy Reaven and colleagues) are currently attempting to adapt these approaches for use in more cognitively impaired ASD samples.

Summary of ASD Anxiety Literature

Overall, the literature suggests that individuals with ASD have higher rates of anxiety than the general population and exhibit both typical and atypical presentations of anxiety. In addition, higher levels of anxiety in ASD are most commonly predicted by higher levels of intellectual functioning and higher levels of specific RRBI symptoms (i.e., insistence on sameness gaining the most support which is likely related to intolerance of uncertainty). Studies indicate clinically significant anxiety symptoms in those with ASD with lower IQs, suggesting that it is a problem across the IQ spectrum. Although we do not yet have clear evidence consistently identifying developmental periods in which anxiety levels may change, it appears that anxiety is frequently seen in individuals with ASD at different points throughout development, including adulthood. Studies have also demonstrated significant decreases in anxiety symptoms post-CBT treatments for those with ASD with average to above average IQs,

and researchers are attempting to adapt these curricula for those with more intellectually impaired presentations.

Quality of Life

One way to measure the clinical impact of behavior outbursts and anxiety is to examine their relations to quality of life. The World Health Organization (WHO) defines QOL as "individuals' perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (World Health Organization, 1998, p. 11). The standard definition of QOL often includes aspects of physical health, psychological health, and social relationships and connectedness (World Health Organization, 1998). Because it incorporates various aspects of wellbeing and satisfaction with one's life, is it important to assess QOL as an outcome domain and intervention target in ASD. As such, it is often assessed in adults with ASD as a marker of outcomes.

The bulk of research on QOL indicates that those with ASD have a lower QOL compared to individuals with typical development and compared to those with other diagnoses (Chiang & Wineman, 2014; van Heijst & Geurts, 2014; Kamp-Becker et al., 2010; Sheldrick et al., 2012; Cottenceau et al., 2012). This suggests that core symptoms associated with an ASD diagnosis increase the likelihood that an individual will have lower QOL. For instance, two systematic reviews have found that QOL is lower for children, adolescents, and adults with ASD compared to peers with typical development (Chiang & Wineman, 2014; van Heijst & Geurts, 2014; Kamp-Becker et al., 2010; Sheldrick et al., 2012; Cottenceau et al., 2012), and that this relationship is characterized by a large effect size (van Heijst & Geurts, 2014). However, the majority of this research has been conducted on children. In a review of 16 studies, Chiang and Wineman (2014) noted that 91% of their sample were children (Chiang & Wineman, 2014). Yet, the evidence that does exist suggests that poor QOL persists into adolescence and adulthood,

with results indicating no age effects for QOL across these developmental time periods (Chiang & Wineman, 2014; Kamp-Becker et al., 2010; van Heijst & Geurts, 2014).

Although having an ASD diagnosis has been found to relate to lower QOL, IQ and ASD symptom severity do not appear to predict QOL (Khanna, Jariwala-Parikh, & West-Strum, 2014; van Heijst & Geurts, 2014; Ying & Cheung, 2013). However, aspects of emotion regulation difficulties, such as maladaptive coping strategies (Khanna et al., 2014) and behavior problems (Chiang & Wineman, 2014), are associated with worse QOL.

Impacts of Anxiety on Individual and Family QOL

Although less frequently investigated, studies have also begun to assess the impact of anxiety on individuals with ASD and their families. Autistic individuals with comorbid anxiety have been found to exhibit more self-injury, higher levels of depression (Kerns et al., 2015), more gastrointestinal problems (e.g., constipation, diarrhea, abdominal pain, bloating, nausea) (Mazurek et al., 2013), and have significantly worse QOL compared to those with ASD without comorbid anxiety (van Steensel et al., 2012). In addition, parents of individuals with ASD with comorbid anxiety diagnoses report higher levels of stress (Kerns et al., 2015) compared to parents of individuals with ASD without anxiety and parents of non-ASD peers with anxiety. Together, these statistics suggest that anxiety plays an important role in outcomes on both individual and familial levels.

Impacts of Behavior Outbursts and Anxiety on Family Burden

Although few studies have examined this construct, another aspect of family QOL is the level of family burden associated with an individual's diagnosis. Measures of family burden typically include the amount of care, time, and money that family members spend supporting their family member and other ways this level of care impacts their life (e.g., ability to attend work). There is scant information published on this domain, but there is evidence that caregivers

of adolescents and young adults with ASD have a high level of family burden associated with caring for their family member, and that burden is significantly greater than seen in other disorders (e.g., Attention Deficit Hyperactivity Disorder) (Cadman et al., 2012). Cadman and colleagues (2012) found that caregiver burden was explained primarily by the individual with ASD's unmet service needs, which other studies have found are extremely high for adults with ASD (Dudley, Klinger, Meyer, Powell, & Klinger, 2019). Furthermore, Cadman and colleagues (2012) found that one's level of depression/anxiety, inappropriate behaviors, and aggression/violence were significant predictors of unmet needs. Thus, although not specifically investigated previously, behavior outbursts and anxiety could be playing a role in increasing family burden. There have been no studies investigating family burden across age in adulthood.

Even with relationships evidenced between behavior outbursts and anxiety with worse QOL for both the individual with ASD and their family, interventions aiming to improve QOL do not often target outbursts or anxiety. More often, interventions aiming to improve QOL attempt to target core ASD symptoms (Bolte & Diehl, 2013; Rogers & Vismara, 2008). An increased focus on behavior outbursts and anxiety to improve QOL and family burden, rather than a primary focus on core ASD symptoms, could prove to be more malleable targets for treatment, as core ASD symptoms are extremely heterogenous and are difficult to change (Bolte & Diehl, 2013).

Connections between Behavior Outbursts and Anxiety in ASD: An Emotion Regulation Framework

Although behavior outbursts and anxiety have typically been studied as completely separate constructs in the ASD field, from a theoretical perspective, it is plausible that they are related to one another. Both behavior outbursts and anxiety could be examined from an emotion regulation framework and be considered products of ineffective emotion regulation coping strategies.

Emotion regulation (ER) is defined as the automatic or intentional ability to initiate, maintain, modulate, and/or modify the occurrence, intensity, and expression of emotions (Thompson, 1994). Research has consistently found that many individuals on the autism spectrum experience significant impairments in ER (e.g., Lerner, Haque, Northrup, Lawer, & Bursztajn, 2012; Loveland, 2005; Mazefsky et al., 2013; Mazefsky et al., 2012) and have even hypothesized that emotion dysregulation may prove intrinsic to the conceptualization of ASD (Mazefsky & White, 2014). Problems with ER have been associated with higher levels of emotional reactivity (e.g., more and higher intensity responses to emotional stimuli with difficulty re-regulating emotions) (Gross, 2002, 2007) and, notably, often connect to both internalizing symptoms (i.e., anxiety, depression) and behavior outbursts in adolescents and young adults with ASD (Cai, Richdale, Dissanayake, & Uljarević, 2018; Mazefsky et al., 2014; Rieffe et al., 2011). Various studies have also indicated that individuals with ASD tend to use more maladaptive ER strategies (e.g., rumination, emotional numbing, avoidance) compared to other populations and the use of these strategies relates to higher levels of psychopathology (i.e., anxiety, depression) (Mazefsky et al., 2014; Samson et al., 2014) and increased behavior problems (Silk, Steinberg, & Morris, 2003). Additionally, emotion dysregulation in children with ASD has also been found to predict increases in both social and behavior challenges across time (Berkovits, Eisenhower, & Blacher, 2017), suggesting that it plays an important role in atypical development of both ASD symptoms and developmental trajectories across the lifespan. In combination, these results suggest that behavior outbursts and anxiety could be products of impaired ER and more related to one another than previously conceptualized.

With the potential for an overarching shared etiology (i.e., emotion dysregulation and lack of adaptive ER coping strategies) between behavior outbursts and anxiety, research examining the relationship between anxiety and behavioral outbursts is needed. The

conceptualization of the ER and anxiety link is relatively new within the typical developmental literature (e.g., Mennin, Heimberg, Turk, & Fresco, 2005) and only recently been explored in the ASD field; only one research team (i.e., White et al., 2014) has begun to theorize the mechanisms through which these domains are connected. Through a developmental psychopathology ER perspective, White and colleagues (2014) have used typical ER development as the foundation of their theory on how these processes go awry in ASD.

In typical development, the theory of the development of emotion regulation involves a variety of complex processes. Infants begin by using co-regulation strategies in which the infant-parent relationship provides the context for beginning to build ER skills through parents helping regulate their child's emotions and socializing them to emotion expression. The preschool and early childhood years, which are marked by periods of linguistic and cognitive growth, involve the use of more self-regulation strategies and increased verbalization of feelings. The most growth in ER skills appears to occur in middle childhood, as children are better able to conceptualize emotions more abstractly, have gained more executive function skills to plan and monitor their behavior, and are better able to regulate their own emotions in different contexts (e.g., social, home, academic) (see Cole et al., 1994, for a review).

White and colleagues (2014) hypothesized that the ER processes seen in typical development go awry in ASD, with the development of emotion dysregulation mediated by neural, psychological, and socio-cognitive mechanisms associated with this diagnosis (e.g., heightened levels of arousal, irregular resting state physiology). Further, they suggest that this impaired ER leads to anxiety, and that this relationship is moderated by the characteristics of ASD (e.g., rigidity, attentional bias, social motivation, sensory issues). Although, this theory has yet to be tested and behavior outbursts were not included in this conceptualization, White and

colleagues (2014) have helped lay the foundation of using an ER lens to examine the relation between anxiety and behavioral outbursts in ASD.

Summary

Although the current ASD population clearly looks different than in previous decades, with higher prevalence numbers, less cognitive impairment, more comorbid psychopathology, and includes a large number of adults, our conceptualization and treatment of behavior outbursts as an associated feature of ASD has experienced little change. Behavior outbursts in those with ASD are frequently viewed as intentional and noncompliant and have generally been treated with behavioral approaches that often do not examine internal factors that could be driving their occurrences. However, anxiety could be having a more significant influence on behavior outbursts than previously conceptualized.

A review of the literature suggests that both anxiety and behavior outbursts occur more frequently in ASD than in other disorders. In addition, a core diagnostic feature of the RRBI domain of ASD, insistence on sameness, has been found to predict both anxiety and behavior outbursts. Knowing that those with ASD often utilize ineffective ER coping strategies, insistence on sameness could be used as a protective mechanism to "cope" with and avoid ER-salient situations. However, when an individual has a greater desire to keep things the same in their life, when things do change, they may respond through an increase in anxiety, which ultimately could lead to a behavior outburst. As such, it is plausible that one form of emotion dysregulation which often begins internally in nature (i.e., anxiety), could present as (or drive) an external form of emotion dysregulation (i.e., behavior outburst). This externalizing response to an internalizing symptom may occur when effective strategies are not used to cope with this anxiety and/or if an individual has difficulty communicating the presence of this anxiety. Thus, an anxiety-driven mediation model could be accounting for the relationship seen between insistence on sameness

and behavior outbursts. In addition, the literature has shown that more behavior outbursts lead to lower individual and family QOL, but, additionally, it is probable that higher levels of anxiety could exacerbate these relationships. To date, no one has conceptualized the link between these variables (i.e., insistence on sameness, behavior outbursts, anxiety, QOL, and family burden). Answering these questions through the testing of theoretically-driven models could expand our understanding of key associated features of ASD.

Present Study

The present study aims to bridge the gap in the literature by modeling and testing relations between insistence on sameness, behavior outbursts, anxiety, individual QOL, and family burden. Specifically, the present study aims to examine whether anxiety is a mediator between insistence on sameness and behavior outbursts, a moderator between behavior outbursts and QOL, and a moderator between behavior outbursts and family burden. In addition to gaining a better understanding of the relationships among these constructs, it is also critical to examine how these constructs may change with age; a review of the literature found scarce information examining these domains beyond adolescence which, again, could inform treatment planning. Since it is plausible that relationships between these constructs and age relationships may differ across levels of intellectual functioning, it is also important to take this variable into account when testing models. As such, these questions will be examined in an intellectually diverse, early to middle adulthood ASD sample. Using an adult sample to test these models could help clarify the ways in which anxiety could be impacting behavior outbursts, provide insight into how these relationships affect adult outcomes (QOL, family burden), and potentially inform treatment planning earlier in development to improve adult outcomes. Aims of the study will be examined for the full sample (Aims 1 and 2), as well across developmental levels (Aim 3) (i.e., good versus poor communication skills) which will be used as a proxy for current IQ.

Thus, the aims and hypotheses of the present study were to:

1. Examine age relationships across adulthood for constructs of interest in the full sample. It was predicted that:

    1a. Insistence on sameness would be present across age and characterized by a linear increase such that as the age of the adults with ASD increases, so too, will insistence on sameness.

    1b. Behavior outbursts would be present across age and characterized by a negative curvilinear relationship in which behavior outbursts slightly decrease across age and then plateau in middle adulthood.

    1c. Anxiety would be present across age and characterized by a positive curvilinear relationship in which anxiety increases across age, but plateaus in middle adulthood.

    1d. Low levels of QOL would be present across ages with no statistically significant change across age.

    1e. Family burden would be present across ages and characterized by a linear increase such that as the age of the adults with ASD increases, so too, will family burden.

2. Test models of behavior outbursts (see Figures 1 & 2) in the full sample. It was predicted that:

    2a. Anxiety would be a mediator between insistence on sameness and behavior outbursts.

    2b. Anxiety would be a moderator between behavior outbursts and QOL. That is, it was hypothesized that behavior outbursts predict QOL, but that anxiety exacerbates this relationship.

2c. Anxiety would be a moderator between behavior outbursts and family burden. That is, it was hypothesized that behavior outbursts predict family burden, but that anxiety exacerbates this relationship.

3. Test Aims 1 and 2 across communication-level subsamples (as a proxy for intellectual ability) to see if these relationships manifest differently across those rated with good communication skills vs. those rated with poor communication skills. It was predicted that:

Age Relationships across Communication-Level Subsamples:

3a. Poor communication skills would be associated with higher levels of insistence on sameness across ages and with a greater increase in insistence on sameness across ages. Good communication skills would be associated with lower levels (although still above average) of insistence on sameness across ages and less of an increase across ages.

3b. Poor communication skills would be associated with higher levels of behavior outbursts across ages and with less change in behavior outbursts across ages. Good communication skills would be associated with lower levels (although still above average) of behavior outbursts across ages and with a slight curvilinear decrease in behavior outbursts across ages (with that decrease plateauing in middle adulthood).

3c. Poor communication skills would be associated with slightly lower levels of anxiety across ages and with less change in anxiety across ages. Good communication skills would be associated with higher levels of anxiety across ages and with a slight curvilinear increase in anxiety levels across ages (with that increase plateauing in middle adulthood).

3d. Both good and poor communication skills would be associated with low levels of QOL across ages and no significant change in QOL across ages.

3e. Both good and poor communication skills would be associated with high levels of family burden with a relatively linear increase in family burden across ages, such that as the age of adults with ASD increases, so too, would family burden for both communication groups.

Models of Behavior Outbursts across Communication-Level Subsamples:

3f. The relationship seen in the full sample (i.e., anxiety mediating insistence on sameness and behavior outbursts) would be consistent and a good fit across communication-level subsamples, but the strength of the relationship would be stronger in the good communication compared to the poor communication group. This was hypothesized due to the potential for caregivers of those with good communication skills to be better able to report on their adult's anxiety symptoms because of the adult's increased ability to communicate the presence of this anxiety. Thus, it was expected that less anxiety would be reported by caregivers of those with poor communication symptoms, decreasing the strength of this relationship.

3g. The relationship seen in the full sample (i.e., anxiety moderating relationship between behavior outbursts and QOL) would be consistent and a good fit across communication groups, but the strength of the relationship would be stronger in the good communication compared to the poor communication group.

3h. The relationship seen in the full sample (i.e., anxiety moderating relationship between behavior outbursts and family burden) would be consistent and a good fit

across communication groups, but the strength of the relationship would be stronger in the good communication compared to the poor communication group.

METHOD

Participants

Participants were 274 caregivers of individuals diagnosed with an ASD by clinicians at the University of North Carolina TEACCH Autism Program (TEACCH), part of the University of North Carolina at Chapel Hill School of Medicine, between 1969 and 2000. TEACCH was funded by the state of North Carolina in 1972, and until 2012 provided diagnostic services free of charge for families across the state of North Carolina through a system of regional outpatient clinics throughout the state. This sample provides the opportunity to examine a large, diverse group of adults with a formal diagnosis of ASD from childhood.

Please see Figure 3 for information regarding the ascertainment process. Participants for this study were recruited from a clinical database of more than 3,000 individuals who were seen at a TEACCH clinic between 1969 and 2000 using the following inclusion criteria: 1) at least 20 years old at the time of the records review; 2) at least one clinical evaluation before the age of 17; 3) met criteria for elevated symptoms of ASD on the Childhood Autism Rating Scale (CARS; Schopler, Reichler, and Rochen Renner 1988) as defined by a score of 27 or higher; and 4) had a confirmed ASD diagnosis in archival clinical records. Using an online search program, we searched for addresses for those that met all inclusion criteria listed above. We located potential addresses for and mailed letters to 1,710 individuals. Of these, we successfully contacted 529 families. We were unable to locate the remaining 1,181 due to a variety of reasons, such as current contact information being unavailable (e.g., home address, phone number), or initial phone calls to discuss interest in the study were not returned. Of the 529 that were successfully contacted via phone, 20 adults with ASD were deceased (4%) and 121 (23%) were determined to not meet final

eligibility criteria for this study due to various reasons (e.g., family could not confirm ASD diagnosis, excluded due to childhood blindness and/or deafness). Of the 432 that were eligible, 354 enrolled (82% enrollment) and 78 declined to participate (18%). Of the 354 who were enrolled in this study, 274 competed the survey (78% completion). One-way ANOVAs were conducted to assess any differences between childhood characteristics for those who completed the study (n = 274), those who enrolled in the study but did not complete their participation (n = 80), and those we were able to contact but declined to participate (n = 78). There were no significant differences between groups on childhood measures of IQ, $F(2, 348) = 2.56$, $p = .08$, although there was a trend for caregivers whose adults had lower IQs to decline participation or not complete their participation. Autism symptom severity as measured by the Childhood Autism Rating Scale (CARS) (Schopler et al., 1988), $F(2, 415) = .33$, $p = .72$, and adaptive behavior as measured by the total Vineland composite score, $F(2,237) = 2.02$, $p = .13$, were not significantly different between groups.

The final sample of adults with ASD for the present study (N = 274, age range 20-58) was 80% male, consistent with the 4.27 ratio of males to females typically reported for ASD (Baio, Wiggins, Christensen, et al. 2018). The sample for this study was identified as 73% Caucasian, 21% African American, and 6% biracial or other races. These race percentages are consistent with the percentages seen in the population of North Carolina from the 1970s to the 1990s. According to the 1980 U.S. Census, 75% of the population was Caucasian, 22% was African American, and 3% were biracial or of another race, making our sample representative of the population at the time of original diagnosis (U.S. Census Bureau, 1983). In terms of current living situation of the adult with ASD at the time of survey completion, 53% lived with family members (n = 145), 10% of the sample lived independently (n = 28), and 37% of the sample

lived in some type of supported living facility (n = 101; i.e., those in supervised housing, group homes, etc.).

Measures

TEACCH Autism in Adulthood Survey. This 87-item caregiver survey measured a variety of demographic variables (e.g., parental education level, adult age and gender) and variables measuring autism outcomes in adulthood, including education level, living situation, recreational activities and social life, adult service needs and utilization, employment status, and level of government benefits. Questions related to caregiver and adult with ASD demographic characteristics, included: 1) adult with ASD's race; 2) maternal education level (1 = some high school education; 2 = high school degree; 3 = vocational training; 4 = some college but no degree; 5 = four-year college; 6 = graduate degree); and 3) caregiver respondent type (e.g., mother, father, other). In addition, this survey assessed for adult current communication ability (i.e., good communication skills [n = 110] or poor communication skills [n = 164]), which was used as a proxy for current intellectual ability in this study. To test whether current communication ability was a reasonable indicator of current intellectual ability, a bivariate correlation was conducted between communication ability and childhood Full-Scale IQ (FSIQ). Childhood FSIQ data was available on 81% of participants and has been shown to have good stability into late adulthood (Begovac, Begovac, Majić, & Vidović, 2009; Deary, Whalley, Lemmon, Crawford, & Starr, 2000). For those that had more than one FSIQ score from different childhood evaluations, the score associated with the oldest childhood age was used in this analysis. A bivariate correlation indicated a significant positive correlation between current communication level and childhood FSIQ, r = .623, p < .001. Thus, since childhood FSIQ is thought to remain relatively stable into adulthood (Begovac et al., 2009; Deary et al., 2000), conversation ability appears to be a reasonable indicator of current intellectual ability.

Social Responsiveness Scale—Adult, Informant Report (2nd Ed.) (SRS-2; Constantino & Gruber, 2012)**.** The SRS-2 is a 65-item caregiver-report form that assesses symptoms associated with ASD. Items are rated on a 4-point Likert Scale from 0 (not true) to 3 (almost always true). The SRS-2 is aligned with DSM-5 criteria for diagnosis of ASD, with two major domains assessed (i.e., social communication and restricted interests and repetitive behaviors). Thus, the SRS-2 contains two higher order indices that correspond to the two symptom domains of ASD: Social Communication and Interaction (SCI) and Restricted Interests and Repetitive Behaviors (RRB). In addition, the SCI and RRB Indices can be summed for a Total SRS-2 score that represents overall ASD symptoms. Higher scores indicate more ASD symptoms. All SRS-2 items were completed by caregivers. The SRS has high internal consistency (.96) (Constantino & Gruber, 2012) and has been found to discriminate well between symptoms of ASD to symptoms associated with other disorders (Mandell et al., 2012). All items of the SRS-2 were completed by caregivers.

Specific questions from the SRS-2 were chosen to create an insistence on sameness measure. Please see Plan of Analyses to reference questions from the SRS-2 and to view which items were summed to create an insistence on sameness variable used in analyses to address present study aims.

Anxiety, Depression, and Mood Scale (ADAMS; Esbensen, Rojahn, Aman, & Ruedrich, 2003). The ADAMS is a 28-item caregiver-report form that assesses anxiety, depression, and other symptoms of psychiatric disorders for the last four weeks in individuals with Intellectual Disability. Items are rated on a 4-point Likert Scale ranging from 0 (not a problem, has not occurred) to 3 (severe problem, occurs frequently), indicating the frequency and severity of symptoms associated with certain behaviors. The ADAMS provides five subscale scores, including: 1) General Anxiety; 2) Social Avoidance; 3) Depression; 4) Manic/Hyperactive; and

5) Obsessive-Compulsive Behavior. Items included in each scale are summed to create a raw subscale score, with higher scores indicating more symptoms. As very few measures exist to assess these symptoms in individuals with Intellectual Disability, the ADAMS was developed to fill this assessment need, and thus, has been recommended for use in samples of individuals with ASD who have a large range of intellectual functioning (Esbensen et al., 2003). The ADAMS has demonstrated high internal consistency with coefficients ranging from .75 to .83 for clinical samples; test-retest reliability is also high, with a mean subscale retest correlation of .78 (Esbensen et al., 2003). The measure is also considered to be clinically meaningful and accounts for comorbid diagnoses (Esbensen et al., 2003). All 28 items of the ADAMS were completed by caregivers. Please see Plan of Analyses to reference questions from the ADAMS and to view which items were summed to create an anxiety measure used in analyses to address present study aims.

Reiss Screen for Maladaptive Behavior (Reiss; Reiss, 1988). The Reiss Screen for Maladaptive Behaviors is a 38-item caregiver-report form that screens for various forms of psychopathology and different types of outward expressions of emotion dysregulation that may have occurred during the last four weeks. The Reiss is designed to assess these symptoms in individuals aged 16 or older with mild, moderate, or severe Intellectual Disability. Items are rated on a 4-point Likert Scale ranging from 0 (not a problem, has not occurred) to 3 (severe problem, occurs frequently), indicating the frequency and severity of symptoms associated with certain behaviors. The Reiss provides eight scale scores, including: 1) Aggressive Behavior; 2) Autism; 3) Psychosis; 4) Paranoia; 5) Depression (behavior signs); 6) Depression (physical signs); 7) Dependent Personality Disorder; and 8) Avoidant Personality Disorder.

For this study, caregivers only completed items from the Aggressive Behavior subscale (i.e., five questions) and three questions assessing specific maladaptive behaviors (i.e., drinking

and drug use, self-injury, and suicidal thoughts). No other questions from the Reiss were given in order to avoid redundancy with other measures used in this study (e.g., SRS-2, ADAMS).

As very few measures exist to assess these symptoms in individuals with Intellectual Disability, the Reiss has frequently been used when working with ASD samples that have a large range of intellectual functioning. Internal reliability is considered high for both the Reiss Total Score (average across samples = .84) and for the Aggressive Behavior scale used in this study (average across samples = .83) (Reiss, 1988). Please see Plan of Analyses to reference questions from the Reiss and to view which items were summed to create a behavior outbursts variable used in analyses to address present study aims.

Quality of Life Questionnaire (QOL-Q; Schalock & Keith, 1993). The Quality of Life Questionnaire is a 40-item caregiver or self-report form that is commonly used to measure a variety of aspects of QOL in individuals with Intellectual Disability. Items are rated on a 3-point Likert Scale, with individual response choices provided from 1 to 3 corresponding to each individual question (e.g., "How much fun and enjoyment do you get out of life?" response choices: 3 = lots, 2 = some; 1 = not much; "How satisfied are you with your current home or living arrangement?" response choices: 3 = very satisfied, 2 = somewhat satisfied, 1 = unsatisfied or very unsatisfied). The QOL-Q provides four subscale scores, including: 1) Satisfaction; 2) Competence/productivity; 3) Empowerment/independence; and 4) Social Belonging. In addition, all subscales are summed to create a Total QOL score, with higher scores indicting better overall QOL. The QOL-Q demonstrates good internal reliability (.90), as well as good construct and concurrent validity (Schalock & Keith, 1993). All QOL-Q items were completed by caregivers.

Family Burden. Seven questions were included in the TEACCH Autism in Adulthood survey assessing family burden associated with the adult with autism. Questions assessed the

following regarding care for the adult with autism in the last 12 months: money spent for care; number of hours spent caring for adult with ASD; amount of time spent coordinating care; financial problems resulting from adult with ASD's condition; impact on family employment decisions (i.e., need to stop working) because of adult with autism's condition; impact on family employment hours because of adult with autism's condition; impact on family employment choices because of adult with autism's condition. Each question was coded on an ordinal scale, with responses indicating higher levels of family burden receiving a higher ordinal score. Scores from each question were summed to create a total family burden score, with higher scores indicating higher levels of family burden. Please see Plan of Analyses to reference questions assessing family burden and to view which items were summed to create a family burden variable used in analyses to address present study aims.

Procedure

The current study was part of a larger study examining ASD in adulthood conducted by the TEACCH Autism Program at the University of North Carolina at Chapel Hill. After contact was made, a potential caregiver participant was screened over the phone for eligibility. Screening questions for eligibility included: 1) confirmation that their adult son or daughter received an ASD diagnosis; 2) confirmation that the caregiver had enough contact with the adult child to answer survey questions; 3) confirmation that the adult child was not blind and/or deaf and did not have significant mobility impairments which could create outliers in the measures assessed.

Once eligibility was established and the caregiver participant verbally indicated their desire to participate, a survey was distributed either electronically or a hard copy was mailed to the participant based on participant preference. The electronic version of the survey was presented by Qualtrics survey software and was distributed to participants by an email that contained a unique link to the survey. Completed surveys were automatically saved on the

Qualtrics server. The paper and pencil version of the survey was distributed by mail, and each packet included a postage-paid envelope for returning the completed surveys. Of the 274 participants, 135 (49%) completed the survey online while the remaining 139 (51%) completed the mailed survey. Informed consent was obtained at the beginning of the survey for both electronic and mailed versions.

The full survey consisted of the following (in order of completion by participants): 1) TEACCH Autism in Adulthood Survey (including Family Burden questions); 2) ADAMS; 3) Reiss; 4) SRS-2; and 5) QOL-Q. Most participants completed the survey within two weeks of receiving it. If the survey was not completed or returned during that time, a follow-up phone call was made. Participants who returned incomplete surveys or whose surveys contained unclear answers were also followed up with a phone call to ensure accurate and complete data collection. This study took between 1 and 2 hours to complete. Participants received $20 for taking part in this study. Prior to beginning recruitment for this study, all necessary approvals from the UNC Institutional Review Board (IRB) were received.

PLAN OF ANALYSES

The majority of the data were analyzed using M-Plus, Version 7, with data management conducted in SPSS Version 25. All data were scored and entered by two research staff to ensure accuracy of the data. Because of missing data for the insistence on sameness variable, two participants were removed from the modeling analyses conducted in Aims 2 and 3. The data was evaluated to ensure it met the assumptions needed to conduct age analyses (i.e., regressions) and model testing (i.e., structural equation modeling), including normality (assessed by central tendency, histograms and Q-Q plots), linearity (assessed by scatterplots with LOESS line), and independence (assessed by scatterplots).

Throughout the analyses, the following were utilized to assess different constructs of interest:

1. Insistence on sameness: was measured by 6 questions from the RRB scale of the SRS-2 that measure behaviors commonly conceptualized as insistence on sameness (see Figure 4 to see SRS-2 items). Higher scores indicate more insistence on sameness. Scores could range from 0-18.
2. Behavior outbursts: was measured by summing items administered from the Reiss, which included the Aggressive Behavior scale and questions assessing maladaptive behaviors. Higher scores indicate higher levels of behavior outbursts. Scores could range from 0-24.
3. Anxiety: was measured by summing the General Anxiety and Obsessive-Compulsive Disorder subscales from the ADAMS. The Social Avoidance subscale was not chosen to be included in this measure of anxiety due to its overlapping nature with core ASD symptoms (e.g., avoiding peers, avoiding eye contact, etc.). Higher scores indicate more anxiety symptoms. Scores could range from 0-30.
4. Quality of life: was measured by the Total QOL score from the QOL-Q. Higher scores indicate better QOL. Scores could range from 40 to 120.
5. Family burden: was measured by the Total Family Burden score from the TEACCH Autism in Adulthood Survey (see Figure 5 for these items from TEACCH Autism in Adulthood survey). Higher scores indicate higher levels of family burden. Scores could range from 0-22.

Demographics and Constructs of Interest

Frequencies were conducted for categorical demographic variables (i.e., type of survey respondent, adult sex, adult race). Means and standard deviations were conducted for continuous demographic variables (i.e., maternal education level, adult age) and constructs of interest (i.e., insistence on sameness, behavior outbursts, anxiety, QOL, and family burden).

Aim 1

To test the first aim of the study, scatterplots were conducted examining age across each construct of interest (i.e., behavior outbursts, anxiety, QOL, family burden) to examine for linearity of relationships for the full sample. Individual regressions were conducted with age entered as the independent variable (IV) and constructs of interest entered as separate dependent variables (DVs).

Aim 2

To test the second (but main) aim of the study, a structural equation modeling (SEM) approach was used to: 1) assess the statistical significance among relationships of interest; 2) examine the strengths of these relationships; and 3) ultimately examine the magnitude of the model fit to test the extent to which the models (see Figures 1 & 2) fit the data from the full sample.

Two models (visualized in Figures 1 & 2) were tested to evaluate: 1) the relationships between insistence on sameness, behavior outbursts, anxiety, and QOL; and 2) the relationships between insistence on sameness, behavior outbursts, anxiety, and family burden.

As this study includes both indicator (i.e., observed constructs directly measured) and latent (i.e., intangible constructs that are measured by three or more indicator variables) variables, two SEM steps occurred: 1) Confirmatory Factor Analysis (CFA) to test the measurement model of the latent variables (i.e., insistence on sameness and family burden; see Figures 4 & 5) to ensure that significant relationships exist between the indicator variables used

to create the latent variable; and 2) Path Analysis to evaluate model fit. To confirm measurement model of the latent variables, indicator variables were entered into the measurement model to test correlations between items, loadings of items in the measurement model, and the overall significance of the measurement model. Modification indices from CFA were used to assess the need to adjust the model (e.g., drop items from the measurement model if they did not significantly load, add measurement error between items). Once the measurement model was confirmed, Path Analysis was conducted. For each model, hypothesized relationships were simultaneously tested to allow direct and indirect paths among the predictors. By doing so, we were able to assess the significance of relationships at three levels: 1) coefficient/parameter level (visualized by the number of arrows in the model; coefficient given for each arrow with a range of 0-1 in which higher values indicate better fit); 2) equation level (visualized by the number of individual equations predicting a DV; R^2 value given for each equation with a range of 0-1 in which higher values indicate better fit); and 3) overall model fit (fit indices listed below given to establish goodness-of-fit).

After simultaneously testing the hypothesized relationships within the model, non-significant relationships were dropped from the model to strengthen it. When results indicated a need for re-specification of a model, changes followed re-specification guidelines and remained theoretically driven. Full mediation of relationships was indicated when one variable did not directly predict the other, but a significant indirect relationship existed between the two variables through another variable (i.e., total relationship = indirect relationship). Partial mediation was indicated when one variable significantly predicted the other, and there was a significant indirect relationship between the two variables through another variable (i.e., total relationship = direct relationship + indirect relationship).

Model fit for CFA and Path Analysis was assessed by multiple conventional goodness-of-fit statistics. Guidelines from Hooper, Coughland, and Mullen (2008), which merge guidelines from Kline (2005) and Boomsma (2000), were used to determine the fit indices used. The indices included in these guidelines were chosen over other fit indices as they have been found to be the least sensitive to sample size, model misspecification, and parameter estimates (Boomsma, 2000; Hooper et al., 2008; Kline, 2005). Based on these guidelines, absolute fit indices included: 1) Model chi-square X^2 ($p > .05$ indicates good model fit); 2) Root Mean Squared Error of Approximation (RMSEA) (values < .10 indicate acceptable model fit, values < .05 indicate good model fit); and 3) Standardized Root Mean Square Residual (SRMR) (values range from 0-1 with values < .05 indicating good model fit). Incremental Fit Indices will include: 1) Comparative Fit Index (CFI) (values range from 0-1 and values > .90 indicate a good model fit against the null (Bentler & Bonnett, 1980). As different fit indices can suggest varying levels of goodness-of-fit, the current study required a model to meet at least three out of four of the fit index qualifications to be determined as an acceptable or good model of the data.

Aim 3

Communication level group differences were assessed for demographic variables and constructs of interest. Pearson Chi-squares were conducted to assess differences between communication groups in maternal education level, type of survey respondent, adult sex, and adult race. Independent samples *t*-tests were conducted to assess differences in age, insistence on sameness, behavior outbursts, anxiety, QOL, and family burden between communication groups.

Since it is plausible that the relationships seen for Aims 1 and 2 may differ by intellectual functioning being that this sample includes a large range of intellectual abilities, Aims 1 and 2 were retested for those with good communication skills versus those who have poor

communication skills (i.e., for communication-level subsamples), as this is a proxy for current IQ in the present study (please see p. 33 of "*Measures*" for more details).

Reexamining Age Relationships Across Communication Groups:

To examine differences in age relationships for constructs of interest across communication groups, communication-level was added as an interaction term to the regressions performed in Aim 1.

Reexamining Models Across Communication Groups:

To examine potential differences in the model results found in the full sample, the final models established in Aim 2 were retested across communication groups. A chi-square test for difference testing was conducted to evaluate whether the measurement parameters of the insistence on sameness variable and the family burden variable could be equated across communication groups. If this test is significant, it indicates that the measurement of these variables should not be equated across groups and it is most appropriate to run the measurement models separately to let parameters vary between groups. Next, path analysis was performed on the finalized models established in Aim 2 to test whether they fit with data of each communication group. Because sample sizes between communication groups (n = 164 for those with poor communication skills, n = 110 for those with good communication skills) were not large enough to reach power of .80, these analyses were considered exploratory and a $p < .10$ significance level was used to indicate significant direct and indirect relationships. The same fit index requirements used in Aim 2 were used to measure overall model fit in Aim 3.

RESULTS

Please see Table 1 for frequencies, means, and standard deviations of demographic variables and constructs of interest for the total sample and across communication groups.

Aim 1

To test examine age relationships of insistence on sameness, behavior outbursts, anxiety, QOL, and family burden, scatterplots were conducted examining age across each construct of interest for the full sample. Relationships appeared flat or slightly linear, with no relationships appearing curvilinear. Thus, age variables were not transformed to assess for curvilinear relationships.

Individual linear regressions were conducted with age entered as the IV and constructs of interest entered as separate DVs to assess changes across adulthood. Age was not a significant predictor of behavior outbursts (p = .84), anxiety (p = .83), or family burden (p = .13). Age was a significant predictor of quality of life, with quality of life worsening across age $F(1, 267) = 7.31$, p = .007, R^2 = .03. Quality of life decreased by .36 points for every 1-year increase in age (see Figure 6). Although age was not a significant predictor of insistence on sameness, $F(1, 267) = 3.50$, p = .06, R^2 = .01), there was a trend for insistence of sameness to increase (by .08 points) for every 1-year increase in age (see Figure 7).

Aim 2

Six questions measured on a Likert scale from the SRS-2 (Constantino & Gruber, 2008) were analyzed with CFA to test the insistence on sameness hypothesized latent variable (see Figure 4). Please see Table 2 for correlations between items. All items demonstrated significant factor loading (p's < .001). CFA indicated poor fit with the data, X^2 (9) = 113.12, p < .001, RMSEA = .21 (90% CI: .17-.24), SRMR = .08, CFI = .89. Modification indices indicated that adding the correlation of the measurement error between SRS-2 insistence on sameness questions 28 and 31 would strengthen the model. After making this modification, CFA indicated good latent variable model fit with the data for four out of the four fit indices, $X^2(8) = 15.40$, p = .05, RMSEA = .06 (90% CI: .00-.10), SRMR = .03, CFI = .99. No major modification indices

were indicated. The finalized latent variable model for insistence on sameness with standardized parameter estimates is presented in Figure 8. This variable was used in path analyses to test fit of Model 1 and Model 2 with the observed data.

Seven questions measured on an ordinal scale from the TEACCH Autism in Adulthood survey were analyzed with CFA to test the family burden hypothesized latent variable (see Figure 5). Please see Table 3 for correlations between items. All items demonstrated significant factor loading (p's < .001). CFA indicated poor fit with the data, $X^2(14) = 72.53$, $p < .001$, RMSEA = .12 (90% CI: .10-.15), SRMR = .09, CFI = .94. Modification indices indicated that adding the correlation of the measurement error between family burden questions 81 and 82 and between questions 80 and 84 would strengthen the model. After making these modifications, CFA indicated good latent variable model fit with the data for four out of the four fit indices, $X^2(13) = 14.31$, $p = .35$, RMSEA = .02 (90% CI: .00-.07), SRMR = .04, CFI = .99. No major modification indices were indicated. The finalized latent variable model for family burden with standardized parameter estimates is presented in Figure 9. This variable was used in path analyses to test fit of Model 1 and Model 2 with the observed data.

SEM analyses indicated that the original hypothesized Model 1 demonstrated poor fit with the data , $X^2(31) = 2525.11$, $p < .001$, RMSEA = .54 (90% CI: .53-.56), SRMR = .29, CFI = .00. With the exception of the relationship between anxiety and QOL ($p = .14$), all relationships within the model were significant (p's < .05). Thus, because of its lack of significance within the model, the path between anxiety and QOL was removed. In addition, because anxiety did not have a direct effect on QOL, the path testing anxiety as a moderator between behavior outbursts and QOL was also removed. After making these modifications to the model, SEM indicated good model fit with the data for three out of the four fit indices, $X^2(24) = 53.19$, $p < .001$, RMSEA = .07 (90% CI: .05-.09), SRMR = .04, CFI = .97. All relationships within the model

were significant and no major modification indices were indicated. The finalized model with standardized parameter estimates is presented in Figure 10, with only significant paths shown for the sake of clarity. There were significant direct relationships between insistence on sameness, anxiety, and behavior outbursts (p's $\leq$ .001). These direct relationships indicated that higher levels of insistence on sameness predicted higher levels of behavior outbursts and more anxiety, and more anxiety predicted significantly higher levels of behavior outbursts. Insistence on sameness accounted for 41% of the variance in anxiety, and insistence on sameness and anxiety accounted for 43% of the variance in behavior outbursts. In addition, there was a significant indirect relationship between insistence on sameness and behavior outbursts through anxiety ($p <$ .001), indicating that anxiety is a partial mediator between these two constructs. In terms of their relationships to QOL, both insistence on sameness ($p <$ .001) and behavior outbursts ($p <$ .001) directly predicted QOL and predicted 24% of the variance in QOL, with higher levels of insistence on sameness and behavior outbursts associated with significantly lower levels of QOL. Lastly, there was a significant indirect relationship of insistence on sameness on QOL through anxiety and behavior outbursts (p = .003), indicating that anxiety and behavior outbursts are partial mediators between insistence on sameness and QOL.

SEM analyses indicated that the original hypothesized Model 2 demonstrated poor fit with the data , $X^2(98) = 1961.77$, $p <$ .001, RMSEA = .26 (90% CI: .25-.28), SRMR = .20, CFI = .30. With the exception of the relationship between behavior outbursts and family burden (p = .20), all relationships within the model were significant (p's $\leq$ .001). Thus, because of its lack of significance within the model, the path between behavior outbursts and family burden was removed. In addition, because behavior outbursts did not have a direct effect on family burden, the path testing anxiety as a moderator of behavior outbursts and family burden was also removed. After making these modifications to the model, SEM indicated good model fit with the

data for four out of the four fit indices, $X^2(85) = 103.59$, $p = .08$, RMSEA = .03 (90% CI: .00-.05), SRMR = .05, CFI = .99. All relationships within the model were significant and no major modification indices were indicated. The finalized model with standardized parameter estimates is presented in Figure 11, with only significant paths shown for the sake of clarity. As discussed within Model 1, the same direct relationships between insistence on sameness, anxiety, and behavior outbursts remained (p's $\leq .001$), with anxiety as a partial mediator between insistence on sameness and behavior outbursts ($p < .001$). In addition, anxiety ($p < .001$) (and not behavior outbursts [$p = .20$] or insistence on sameness [$p = .37$]) directly predicted family burden and explained 15% of the variance in family burden, with higher levels of anxiety associated with significantly higher levels of family burden. Lastly, there was a significant indirect relationship of insistence on sameness on family burden through anxiety ($p < .001$), indicating that anxiety is a full mediator between the relationship of insistence on sameness and family burden.

Aim 3:

Pearson Chi-Squares were conducted to assess potential differences in demographic variables between communication groups. There were no significant differences in maternal education level ($p = .14$), type of survey respondent ($p = .11$), adult sex ($p = .34$), or adult race ($p = .39$) between groups. Independent sample t-tests were conducted to assess differences in age, SRS-2 total, insistence on sameness, behavior outbursts, anxiety, QOL, and family burden between communication groups. There were significant differences across communication-level groups in age, $t(272) = 3.12$, $p = .002$, SRS-2 total score, $t(261)=8.38$, $p<.001$, insistence on sameness, $t(267) = 3.28$, $p = .001$, behavior outbursts, $t(265) = 3.85$, $p < .001$, anxiety, $t(270) = 4.29$, $p < .001$, QOL, $t(267) = -7.77$, $p < .001$, and family burden, $t(268) = 3.58$, $p < .001$. Compared to those with good communication skills, those with poor communication skills were significantly older ($M = 36.38$, $SD = 6.72$; good communication: $M = 33.92$, $SD = 5.94$), had

worse total autism symptoms (M = 105.80, SD = 28.79; good communication: M = 74.67, SD = 30.54), had higher levels of insistence on sameness (M = 10.55, SD = 4.35; good communication: M = 8.74, SD = 4.51), had higher levels of behavior outbursts (M = 4.47, SD = 4.37; good communication: M = 2.58, SD = 3.28), had higher levels of anxiety (M = 8.61, SD = 5.73; good communication: M = 5.64, SD = 5.64), had lower levels of QOL (M = 72.31, SD = 12.75; good communication: M = 84.93, SD = 13.51), and higher levels of family burden (M = 13.10, SD = 4.94; good communication: M = 10.94, SD = 4.74).

To examine potential differences in age relationships for constructs of interest across communication groups, communication-level was included as an interaction term to the regressions performed in Aim 1. There were no significant interactions between communication level on changes across age for insistence on sameness, behavior outbursts, anxiety, QOL, or family burden (p's = .15-.88). Thus, there were no significant differences in the effect of age on variables of interest across communication level groups.

The final insistence on sameness latent variable established for the full sample in Aim 2 was tested for fit across communication groups. A chi-square test for difference testing was conducted to evaluate whether the measurement parameters of the insistence on sameness variable can be equated across communication groups. Results indicated that the restricted model (holding parameters equal) was significantly worse than the unrestricted model (allowing parameters to vary across communication groups), $X^2(25)= 81.90$, $p < .001$. Thus, the insistence on sameness latent variable from the full group was tested separately across communication groups.

Please see Table 4 for correlations between insistence on sameness items for those with poor communication skills. All items demonstrated significant factor loading (p's $\leq .001$). For those with poor communication skills, CFA indicated good latent variable model fit with the data

for four out of the four fit indices, $X^2(8) = 9.77$, $p = .28$, RMSEA = .04 (90% CI: .00-.10), SRMR = .03, CFI = .99. No major modification indices were indicated. These results indicated that the same latent variable used to measure insistence on sameness in the full sample is a good fit for those with poor communication skills. This variable was used in path analyses to test fit of Model 1 and Model 2 for those with poor communication skills.

Please see Table 5 for correlations between insistence on sameness items for those with good communication skills. All items demonstrated significant factor loading (p's < .001). For those with good communication skills, CFA indicated acceptable latent variable model fit with the data for three out of the four fit indices, $X^2(8) = 17.84$, $p = .02$, RMSEA = .10 (90% CI: .04-.17), SRMR = .04, CFI = .97. No major modification indices were indicated and all items within the model were significant. These results indicated that the same latent variable used to measure insistence on sameness in the full sample demonstrated acceptable fit for those with good communication skills. This variable was used in path analyses to test fit of Model 1 and Model 2 for those with good communication skills.

The finalized QOL model found in Aim 2 (i.e., Figure 10) was tested for fit with those with poor communication skills. SEM indicated good model fit with the data for three out of the four fit indices, $X^2(24) = 38.05$, $p = .03$, RMSEA = .06 (90% CI: .02-.09), SRMR = .05, CFI = .98. All direct and indirect relationships within the model were significant (p's < .02) and no major modification indices were indicated, suggesting that the QOL model found in the full sample is a good fit for those with poor communication skills.

The finalized QOL model found in Aim 2 (i.e., Figure 10) was tested for fit with those with good communication skills. SEM indicated good model fit with the data for three out of the four fit indices, $X^2(24) = 38.62$, $p = .03$, RMSEA = .07 (90% CI: .02-.12), SRMR = .05, CFI = .97. All direct and indirect relationships within the model were significant (p's < .06) and no

major modification indices were indicated, suggesting that the QOL model found in the full sample is a good fit for those with good communication skills.

Testing of Family Burden Latent Variable Across Communication Groups:

The final family burden latent variable established for the full sample in Aim 2 was tested for fit across communication groups. A chi-square test for difference testing was conducted to evaluate whether the measurement parameters of the family burden variable can be equated across communication groups. Results indicated that the restricted model (holding parameters equal) was significantly worse than the unrestricted model (allowing parameters to vary across communication groups), $X^2(30)= 90.82$, $p < .001$. Thus, the family burden latent variable from the full group was tested separately across communication groups.

Please see Table 6 for correlations between family burden items for those with poor communication skills. All items demonstrated significant factor loading (p's < .001). For those with poor communication skills, CFA indicated good latent variable model fit with the data for four out of the four fit indices, $X^2(13) = 18.52$, $p = .14$, RMSEA = .05 (90% CI: .00-.10), SRMR = .04, CFI = .99. No major modification indices were indicated. These results indicated that the same latent variable used to measure family burden in the full sample is a good fit for those with poor communication skills. This variable was used in path analyses to test fit of Model 1 and Model 2 for those with poor communication skills.

Please see Table 7 for correlations between family burden items for those with good communication skills. All items demonstrated significant factor loading (p's < .001). For those with good communication skills, CFA indicated acceptable latent variable model fit with the data for three out of the four fit indices, $X^2(13) = 20.88$, $p = .08$, RMSEA = .08 (90% CI: .00-.13), SRMR = .06, CFI = .98. No major modification indices were indicated and all items within the model were significant. These results indicated that the same latent variable used to measure

family burden in the full sample demonstrated acceptable fit for those with good communication skills. This variable was used in path analyses to test fit of Model 1 and Model 2 for those with good communication skills.

The finalized family burden model found in Aim 2 (i.e., Figure 11) was tested for fit with those with poor communication skills. SEM indicated good model fit with the data for three out of the four fit indices, $X^2(85) = 96.19$, $p = .19$, RMSEA = .03 (90% CI: .00-.05), SRMR = .06, CFI = .99. Although slightly less strong than in the full sample, all direct and indirect relationships within the model were either significant (p's < .08) or trending towards significance ($p = .11$). No major modification indices were indicated, suggesting that the family burden model found in the full sample is a good fit for those with poor communication skills. Although not significant at the $p < .10$, the indirect relationship of insistence on sameness on family burden through anxiety that was present in the full sample was trending towards significance in the same direction for those with poor communication skills ($p = .11$). Overall, it appears that the same pattern of relationships found in the finalized family burden model in Aim 2 was consistent for those with poor communication skills.

The finalized family burden model found in Aim 2 (i.e., Figure 11) was tested for fit with those with good communication skills. SEM indicated good model fit with the data for three out of the four fit indices, $X^2(85) = 104.81$, $p = .07$, RMSEA = .05 (90% CI: .00-.07), SRMR = .08, CFI = .97. No major modification indices were indicated, suggesting that the family burden model found in the full sample is a good fit for those with good communication skills. All direct and indirect relationships within the model were significant and remained the same from the full sample (p's < .01), with the exception of one direct relationship. Although the model would be drawn in the same way as in the other samples, there was no longer a direct relationship between insistence on sameness and behavior outbursts ($p = .78$). However, the significant indirect

relationship of insistence on sameness to behavior outbursts through anxiety (p = .01) remained, indicating that anxiety is a full mediator (in comparison to a partial mediator in the other samples) between these two constructs.

DISCUSSION

The current study examined data from a relatively large, statewide sample of adults with ASD who received a formal diagnosis of ASD in childhood at the University of North Carolina TEACCH Autism Program. Specifically, the current study aimed to reconceptualize behavior outbursts in adults with ASD as being related to underlying emotion regulation difficulties (i.e., anxiety). Overall, the results of this study supported the role of anxiety in predicting and mediating behavior outbursts, as well as having direct and indirect negative impacts on family burden and QOL in adults with ASD.

The current study's findings support the original hypothesis that anxiety is a mediator between insistence on sameness and behavior outbursts. Results indicated that insistence on sameness in adults with ASD directly impacted both anxiety and behavior outbursts, with higher levels of insistence on sameness predicting more anxiety and behavior outbursts. In addition, both insistence on sameness and anxiety directly affected behavior outbursts, with higher levels of each of these constructs predicting more behavior outbursts. Importantly, anxiety partially accounted for the relationship seen between insistence on sameness and behavior outbursts. Thus, anxiety is playing a direct and indirect role in increasing behavior outbursts for adults with ASD.

The current study's results support previous research, while also substantially adding to the literature. Aligned with prior findings, insistence on sameness, which is a core diagnostic feature of the RRBI domain in ASD, was found to predict both anxiety (Rodgers, Glod, Connolly, & McConachie, 2012; Uljarević et al., 2017) and behavior outbursts (Maddox et al.,

2017). In addition, although anxiety had yet to be tested as a mediator of the relationship between insistence on sameness and behavior outbursts, it theoretically aligns with an emotion regulation conceptualization of the relationships between these constructs. Insistence on sameness could be conceptualized as a core ASD protective mechanism to "cope" with and avoid situations in which ER strategies may be needed. However, when an individual is unable to maintain "sameness," increased anxiety may occur and lead to a behavior outburst. As such, although not previously conceptualized, it appears that one form of emotion dysregulation which often begins internally (i.e., anxiety) is partially accounting for an external form of emotion dysregulation (i.e., behavior outburst).

These findings emphasize the clear impact of anxiety on behavior outbursts for adults with ASD. Anxiety not only directly predicts behavior outbursts, but is also a mechanism through which a facet of core ASD symptoms leads to more behavior outbursts. The literature has consistently demonstrated the significant consequences that behavior outbursts have on those with ASD. Not only do they create challenges to service access and acquisition of new skills (Borthwick-Duffy et al., 1987; Chadwick et al., 2000), but they are also the leading cause of psychiatric hospitalizations for those on the autism spectrum (Mandell, 2008; Siegel & Gabriels, 2014). This is especially important for adults with ASD, given the barriers they already encounter accessing services (Dudley et al., 2019) and the documented increase in psychiatric hospitalizations with age (Mandell, 2008; Siegel & Gabriels, 2014). Thus, it is important to understand and treat behavior outbursts; these results suggest that anxiety should be included as a construct of interest when examining and treating behavior outbursts.

The current study's findings demonstrated that anxiety directly and indirectly impacted outcomes for adults with ASD. Results indicated that more anxiety, and not behavior outbursts or insistence on sameness, directly predicted increased family burden. In addition, anxiety fully

mediated the relationship between more insistence on sameness leading to increased family burden. In terms of QOL, more insistence on sameness and behavior outbursts, and not anxiety, directly predicted worse QOL. However, both anxiety and behavior outbursts partially accounted for the relationship between more insistence on sameness leading to worse QOL.

Overall, these results match with past research demonstrating that anxiety has negative impacts on family stress (Kerns et al., 2015) and that behavior outbursts decrease QOL (Borthwick-Duffy et al., 1987) in individuals with ASD. This suggests that anxiety may be a primary treatment target to improve family burden and is playing a key role in family outcomes. With regards to predictors of QOL, anxiety and behavior outbursts played an indirect role in impacting QOL. However, contrary to expectations, anxiety did not play a direct role on QOL or moderate the relation between behavioral outbursts and QOL. The fact that anxiety directly impacted family burden but not adult QOL suggests that these two measures are tapping into different aspects of adult outcome. For example, the QOL measure includes community integration activities (e.g., employment, social activities) that may be restricted due to behavioral outbursts but not necessarily anxiety. Alternatively, this discrepancy between family burden and adult QOL could also be partially explained by the fact that caregivers were reporting on their own family's burden in caring for the adult with ASD and may have been more accurate in doing so. It is possible that future research could find direct relationships between anxiety and decreased QOL if multiple methods are used to measure these constructs, including some type of self-report measure.

In general, the same model relationships demonstrated in the full sample were present for those with poor communication skills and those with good communication skills. Notably and as hypothesized, the significance of anxiety in predicting behavior outbursts and outcomes was supported for both those with poor communication skills and those with good communication

skills. However, anxiety played a stronger role in the relationships among constructs and their relationships to family burden for those with good communication skills; within the family burden model for those with good communication, anxiety fully accounted for the relationship between insistence on sameness and behavior outbursts and was a stronger predictor of family burden.

The idea that anxiety may be playing a more prominent role in overall functioning and family outcomes for those with better intellectual functioning compared to those who are more intellectually impaired has been posited by past research (e.g., Dubin, Lieberman-Betz, & Michele Lease, 2015; Gotham, Brunwasser, & Lord, 2015; Hallett, Lecavalier, Sukhodolsky, & Cipriano, 2013; Kerns et al., 2015; Morrow Kerns et al., 2014). Those with average to above average IQs tend to demonstrate greater insight into their own anxiety, as well as are better able to verbally communicate the presence of anxiety compared to those with lower IQs. For those who are more intellectually impaired (i.e., those with poor communication skills), more factors may be impacting the occurrence of behavior outbursts and the impact on the family (e.g., inability to verbally communicate, frustration from lack of understanding, need for more support from family). However, it is noteworthy that similar relationships found in the full sample were present for both those with good communication and poor communication skills; results indicate that anxiety is still playing a significant role, although to different extents, across the intellectual spectrum for this sample of adults with ASD. These results suggest the need to better understand how to assess and treat anxiety for those with ASD with and without ID. Although those with ASD and ID may not be able to verbally communicate their anxiety in the same ways as those without intellectual impairments, the current findings indicate that it should still play a role in assessment and treatment for those across the IQ spectrum.

Overall, results from this study indicated that those with poor communication skills were significantly more impaired on every construct of interest examined in this study (i.e., insistence on sameness, anxiety, behavior outbursts, QOL, family burden). Some of these results are supported by past research, whereas others differ from hypotheses and the literature. For instance, lower intellectual ability has been associated with more autism symptoms (McGovern & Sigman, 2005; Taylor & Seltzer, 2010), increased behavior outbursts (e.g., Mctiernan et al., 2011; Murphy et al., 2009), and more family burden (Al-Krenawi, Graham, & Al Gharaibeh, 2011); the current study's results align with these findings. In contrast to current findings, those with higher IQs and better language skills have typically been thought to have more anxiety than those who are more intellectually impaired (Dubin et al., 2015; Gotham et al., 2015; Hallett et al., 2013; Kerns et al., 2015; Morrow Kerns et al., 2014). In addition, unlike current findings, differing levels of intellectual functioning have generally not been supported to predict QOL for those with ASD (Khanna et al., 2014; van Heijst & Geurts, 2014; Ying & Cheung, 2013). It is possible that previous studies using self-report did not accurately assess anxiety or QOL in those with significant communication and intellectual delays; thus, the use of caregiver report in the current study may be a more accurate measure of anxiety in those with developmental delays and ASD. However, it is also possible that caregivers of those with poor communication skills were overreporting their adult son or daughter's anxiety symptoms. Yet, it is notable that group means on these measures were not approaching measurement basals or ceilings. Therefore, it may be that our sample of adults with poor communication skills who were diagnosed in childhood is truly more impaired in these areas. If so, these results suggest that anxiety should not be thought of as a "high functioning" problem and should be assessed and treated in this population. Importantly, results indicate that adults with ASD who are more intellectually impaired may at

increased risk for more impaired functioning and poorer individual and family outcomes, suggesting the need for targeted intervention in these areas.

In terms of age relationships, the current study's findings demonstrated that QOL significantly worsened across adulthood and that there was a trend for insistence on sameness to increase across adulthood. There were no evidenced changes in anxiety, behavior outbursts, or family burden in this cross-sectional middle adulthood sample. The significant QOL decline across adulthood in this cross-sectional study suggests the need for continued intervention to target QOL and that this may be especially important as adults with ASD age. Notably, the current QOL measure focuses on community integration rather than issues of physical health that are often used in other measures. Thus, differences in QOL across age could be related to the construct measured. It could also suggest that the older cohorts in our sample are in need of increased interventions targeting their QOL. This result differs from other studies in which no age effects on QOL were seen in adolescence and adulthood (Chiang & Wineman, 2014; Kamp-Becker et al., 2010; van Heijst & Geurts, 2014). However, in comparison to other studies, our sample consisted of adults with ASD who were diagnosed in childhood, which may indicate that our sample is more impaired compared to those who include individuals who were diagnosed with ASD later in their development. Studies have yet to investigate the time of ASD diagnosis in relation to QOL changes across development, which could potentially explain the current study's differing results. In addition, the current study's findings documented a less than one-point decrease in QOL per one-year age increase; given that the QOL measure had a 66-point range across the entire sample, the clinical significance of this small decrease is unclear.

The trend for insistence on sameness to increase across adulthood aligns with the broader non-ASD developmental research suggesting that individuals tend to decrease in their openness to new experiences and increase in rigidity of routine as they age (Allemand, Zimprich, &

Hertzog, 2007; Donnellan & Lucas, 2008). The overarching models found in this study suggest that insistence on sameness plays a critical role in both symptom relationships and outcomes for those with ASD; if insistence on sameness is trending in its increase across adulthood, it may exacerbate the challenges and poor outcomes associated with this domain for those with this disorder (i.e., higher levels of anxiety, behavior outbursts, lower levels of QOL). However, again, the clinical significance of this less than one-point increase in insistence on sameness per every one-year age increase is unclear. Yet, given the smaller possible range of the insistence on sameness measure in comparison to the QOL measure, this increase could have meaningful impacts across aging. To address this question, it will be important that future research seek to examine the confluence of typical aging with ASD symptomatology to better understand if/how these potential increases impact daily life.

Diverging from prior research, behavior outbursts did not significantly change across adulthood in this cross-sectional sample. In comparison, prior research supported decreases in behavior outbursts during these developmental periods (Gray et al., 2012; Shattuck et al., 2007; Taylor & Seltzer, 2010). However, each of these studies documenting this decrease were longitudinal, began in childhood or early adolescence (rather than solely in early to middle adulthood), and used a different measure to assess behavior outbursts. These distinctions in study design and sample age range could account for the current study's results. In terms of anxiety and family burden, only two known studies that include adults with ASD have investigated changes in anxiety (one cross-sectional, one longitudinal) (Davis et al., 2011; Gotham et al., 2015) and family burden has also been infrequently studied in the literature. Overall, this study adds to the limited research examining these constructs in early to middle adulthood across the IQ spectrum.

In this intellectually diverse sample of adults with ASD, anxiety partially accounted for the relationship between insistence on sameness (i.e., an aspect of core ASD symptoms) predicting more behavior outbursts. Notably, anxiety was not only a partial mediator of behavior outbursts, but indirectly accounted for decreases in QOL for the individual with ASD and directly and indirectly predicted family burden in caring for their adult with autism. Thus, anxiety appears to be a connecting factor between key areas of functioning and outcomes.

The most common means of assessing behavior outbursts is through functional behavior analysis (FBA). One of the primary goals of FBA is to determine the function of a behavior, which frequently includes evaluating the following function categories: desires to get something (e.g., attention, activity/item, sensory stimulation); desires to avoid, delay or escape something (e.g., attention, activity/item, sensory stimulation) (Sugai, Lewis-Palmer, & Hagan-Burke, 2000). The results of this study suggest that it may be beneficial to include a formal assessment of anxiety in FBA, or at the very least, include anxiety as possible communicative function or "why*"* behind a behavior.

In terms of treatment, behavior outbursts have historically been targeted through ABA and discipline strategies (see Klinger & Dudley, 2019, for a review). However, these approaches generally ignore the internal factors, such as anxiety, through which behavior outbursts could be occurring (e.g., antecedent→*anxiety increase*→behavior outburst→consequence). The current findings suggest that anxiety could be targeted to improve behavior outbursts and family burden, and that both behavior outbursts and anxiety could be targeted to improve QOL. Interventions aiming to improve QOL and decrease family burden have attempted to primarily target core ASD symptoms (Bolte & Diehl, 2013; Rogers & Vismara, 2008). Yet, these results suggest that anxiety may be an important construct to consider when aiming to improve behavior outbursts, QOL, and family burden. An increased focus on anxiety to improve individual and family

outcomes could prove to be a more malleable treatment target, as core ASD symptoms are extremely heterogenous and are difficult to change (Bolte & Diehl, 2013).

As a clinical example of how we could integrate the assessment and treatment of anxiety driving behavior outbursts in ASD, we can imagine a young adult having a behavior outburst in which he sits at his seat crying, screaming, and punching a wall rather than transitioning to lunch with his peers. In this instance, an FBA would likely be conducted to determine the function of the outburst. Data from the FBA may suggest that the function of the behavior is to avoid, delay, or escape going to lunch with peers. For some onlookers, this outburst may be perceived as oppositional, especially if the young adult is given a command (e.g., "You must go to lunch now") directly prior to the behavior outburst. In this case, the outburst may be treated through punishment and/or reward strategies to change the consequences in response to the outburst. However, if the FBA also included an assessment of potential anxiety influencing the outburst (e.g., anxiety resulting in an outburst due to social anxiety in response to lunch), then the inclusion of anxiety treatment strategies may also be beneficial in treating this behavior. For instance, in addition to classic behavioral strategies, this young adult may also benefit from learning coping skills to help his body calm down when feeling anxious about going to lunch, using positive self-talk (e.g., "I can do this. I can tolerate this anxiety"), and exposure and response prevention therapy to target social anxiety related to interacting with others at lunch. If anxiety is not included in assessment and potential conceptualization of behavior outbursts, a critical intervention target may be missed.

Results from recent RCTs have indicated that anxiety can be effectively targeted through CBT interventions for those with ASD with average to above average IQs (Reaven et al., 2012, 2011; Scarpa & Reyes, 2011; Wood et al., 2015), which is encouraging given the current study's findings regarding the significance of anxiety in affecting functioning and outcomes. Less is

known about effective methods for treating anxiety for those with ASD who have lower intellectual functioning. However, research results have suggested that anxiety can be successfully treated for those with ID. For instance, the use of graded exposure and reinforcement has been effective in treating some types of anxiety for those with ID with and without ASD (Jennett & Hagopian, 2008). In addition, mindfulness-based relaxation therapy has been found to reduce anxiety and maladaptive behavior in individuals with ID without ASD and improve coping and stress management in parents and caregivers of those with ID (Robertson, 2011). Leading anxiety researchers in the ASD field (i.e., Judy Reaven and colleagues) are also currently evaluating ways to target cognitions for children with ASD with mild to moderate ID. In their adapted CBT intervention, the teaching and practicing of short scripts for when children are facing their fears (e.g., "I can do this!"; "I am brave!") is used to target underlying anxiety cognitions. The findings from the current study demonstrating the importance of anxiety, in combination with the promising results from intervention studies for those with and without ID, suggest the need to continue to increase our understanding of the assessment and treatment of anxiety for those with ASD.

The current study offers a number of limitations and areas for future research, particularly related to issue of accurate measurement in a diverse sample of adults with ASD experiencing a range of intellectual and communication abilities. First, a clear limitation to this study is that data measuring the constructs of interest were gathered through caregiver report and were not reported by the adults with ASD. In particular, anxiety, which begins internally and may or may not come with an outward expression of that anxiety, is best reported by the individual themselves, through more comprehensive clinical interviews, and/or through methods that directly measure physiological arousal. To attempt to address this limitation, the caregiver reported anxiety measure chosen for this study (i.e., the ADAMS) primarily includes behaviors

or reactions associated with anxiety that are noticeable to an observer and has been validated as a report measure for caregivers of adults with ID (Esbensen et al., 2003; Hagopian & Jennett, 2008). Thus, the current findings suggest that when one's anxiety is noticeable to others, it drives behavior outbursts and is directly and indirectly related to family burden and indirectly related to QOL. However, it is unclear the extent to which caregivers *did not* notice an anxiety response in their adult with ASD. Along with the caregiver report limitations, because results were obtained via caregiver survey, current intellectual functioning was not available. While communication skills served as a proxy for intellectual functioning, future research should clarify whether potential differences exist in the findings based on current FSIQ.

In addition, although the ADAMS is the most commonly used measure of anxiety for samples that include a large intellectual functioning range, some of its items do not clearly differentiate anxiety from ASD symptoms (e.g., easily upset if ritualistic behaviors are interrupted is listed as an OCD item, but also relates to ASD) and could be impacting study results. ASD differential diagnosis with other disorders and between anxiety disorders is particularly important for this population, as core ASD symptoms can be difficult to differentiate from other symptoms (e.g., OCD). Future research should aim to replicate and expand the current findings by using a variety of measures to assess anxiety. The literature has indicated that a combination of report forms, clinical interviews, direct observation of behavior, and measures that do not require direct observation of an anxiety reaction (e.g., heart rate sensor, respiration sensor) may help in determining whether an individual meets DSM criteria for specific anxiety disorder(s) (Hagopian & Jennett, 2008).

Another limitation to interpretability of results includes the acknowledgement that the current study was not a population-based study. Only a portion of those who originally received ASD diagnoses at a TEACCH clinic between 1969 and 2000 were located for this study. While

this study made extensive efforts to contact and recruit all individuals who met the study criteria, we do not know whether the current sample represents the full population of adults with ASD, including those who we were unable to contact. It is possible that those who we were unable to contact (largely because no phone number was found 10 to 30 years after initial diagnosis) may have different characteristics than those who participated in this study. However, the fact that our study is representative of the race and ethnicity demographics in North Carolina at the time of childhood diagnosis and the fact that all services were provided free of charge during childhood, offers some indication that we were able to recruit a relatively representative sample of adults who were diagnosed in childhood.

This study also did not include individuals who were diagnosed with ASD during adulthood. The decision to focus on adults diagnosed as children was based on the fact that childhood clinical records were available to confirm diagnosis (which many studies are unable to do) and we wished to examine ASD in adulthood for those who had lived with this diagnosis since childhood (i.e., not those newly diagnosed). Because later diagnoses are often indicative of fewer symptoms and/or higher intellectual skills (Mandell, Novak, & Zubritsky, 2005), the current sample may be more impaired than those who were diagnosed later in their development. While communication level did not impact study findings, it is possible that inclusion of adults diagnosed later in life may show different relationships between the constructs of interest in this study. Future research should seek to replicate these findings through a population-based study design including adults who were diagnosed later in life. Including individuals diagnosed with ASD in adulthood may provide additional information about anxiety and behavior outbursts and their relationships to outcomes, as this group of adults may be qualitatively different from the current sample.

Additionally, due to the cross-sectional nature of this study, we cannot make clear causation statements. Although SEM was used and is a powerful tool to test theoretically driven models that posit directionality of relationships (i.e., whether one construct predicts another), it is likely that some of these relationships are bi-directional. In addition, because this study is not longitudinal, it is unclear what the true causal variables are within the final model of relationships between insistence on sameness, behavior outbursts, anxiety, QOL, and family burden. Therefore, future longitudinal research is needed to test whether anxiety in childhood predicts increases in behavioral outbursts across time and less optimal adult outcome.

Finally, it is imperative that future research work to consistently assess for anxiety in individuals with ASD and evaluate the best ways to treat anxiety in this complex and heterogenous disorder. The current findings indicate that anxiety is a mechanism through which insistence on sameness leads to behavior outbursts, lower QOL, and higher levels of family burden and that similar relationships exist for those with different levels intellectual functioning. As a field, if we can better assess for and treat anxiety across the ASD spectrum, outcomes could improve on both the individual and familial levels. Currently, while CBT is the hallmark of adult interventions in the general population and has been effective in treating anxiety in children and adolescents with ASD (Reaven et al., 2012; Storch et al., 2013; Sung et al., 2011; Wood et al., 2009), to date, there have been no RCTs addressing the treatment of anxiety in adults with ASD. The current findings suggest that this is a critical gap in the treatment literature and one that future research should address. It may also be true that for certain individuals with ASD, some interventions aimed at treating behavior outbursts and improving QOL and family burden may be more effective than others. For instance, a combination of cognitive and behavioral strategies targeting both anxiety and behavior outbursts may be most effective for some individuals with ASD, whereas a different combination of intervention targets and treatment strategies may be

more effective for others. Future research should aim to address these complex questions to make treatment more individualized for the growing number of adults with ASD and their families.

The results of this study are the first of its kind to demonstrate the clear importance of anxiety in impacting behavior outbursts, QOL, and family burden in adults with ASD. Anxiety directly predicted more behavior outbursts, increased family burden, and fully accounted for the relationship between insistence on sameness predicting more family burden. In addition, both behavior outbursts and anxiety were key mechanisms through which insistence on sameness decreased QOL. Notably, the importance of anxiety was supported for those with both lower and higher levels of intellectual functioning. Overall, the current findings clearly document the need to assess for and treat anxiety as a potential means to improve both individual and familial outcomes in adulthood.

Table 1. Demographic characteristics for the caregiver and the individual with ASD at time of adult survey. Data for total sample and groups by communication level (Mean & SD, unless otherwise noted).

	Total Sample	Poor Comm.	Good Comm.	Statistic χ^2 or *t*, *p* value for comparison between poor and good comm. groups
	(*N*=274)	(*n*=164)	(*n*=110)	
Caregiver Demographics				
Maternal Education Level (*4=some college but no degree*)	4.47 (1.3)	4.38 (1.37)	4.61 (1.08)	*t*(268)=-1.49, *p*=.14
Survey Respondent (% mothers)	72%	68%	77%	$\chi^2(1)=2.63$, *p*=.11
Adult with ASD Demographics				
	Total Sample	Poor Comm.	Good Comm.	Statistic χ^2 or *t*, *p* value for comparison between poor and good comm. groups
Sex (% male)	80	78	83	$\chi^2(1)=.90$, *p*=.34
Caucasian (%)	73%	71%	76%	$\chi^2(1)=.74$, *p*=.39
Age (in years)	35.4 (6.5)	36.38 (6.72)	33.92 (5.94)	*t*(272)=3.12, *p*=.002
SRS-2 Total (Raw)	93.37(33.17)	105.80 (28.79)	74.67(30.54)	*t*(261)=8.38, *p*<.001

IS Total Symptoms (Raw)	9.83 (4.50)	10.55 (4.35)	8.74 (4.51)	$t(267)=3.28$, $p=.001$
Behavior Outbursts Total Symptoms (Raw)	3.70 (4.06)	4.47 (4.37)	2.58 (3.28)	$t(265)=3.85$, $p<.001$
Anxiety Total Symptoms (Raw)	7.42 (5.75)	8.61 (5.53)	5.64 (5.64)	$t(270)=4.29$, $p<.001$
QOL Total (Raw)	77.38 (14.43)	72.31 (12.75)	84.93 (13.51)	$t(267)= -7.77$, $p<.001$
Family Burden Total (Raw)	12.23 (4.97)	13.10 (4.94)	10.94 (4.74)	$t(268)=3.58$, $p<.001$

All Total scores are raw, unstandardized scores.
Comm – Communication; SRS-2 – Social Responsiveness Scale, Second Edition; IS – Insistence on sameness;
QOL – Quality of life.

Table 2. Correlation matrix for CFA of insistence on sameness latent variable for full sample.

Observed Variable	1.	2.	3.	4.	5.	6.
1. Rigid or inflexible behavior	—					
2. Difficulty with change	**.52**	—				
3. Thinks of talks about the same things	**.26**	**.21**	—			
4. Can't get mind off something	**.35**	**.43**	**.60**	—		
5. Narrow range of interests	**.31**	**.36**	**.23**	**.16**	—	
6. Inflexible, hard time changing mind	**.44**	**.60**	**.24**	**.46**	**.34**	—

All values in bold print are significant ($p < .05$).

Table 3. Correlation matrix for CFA of family burden latent variable for full sample.

Observed Variable	1.	2.	3.	4.	5.	6.	7.
1. Money spent on care	—						
2. Hours/week spent providing care	**.38**	—					
3. Hours/week coordinating care	**.31**	**.65**	—				
4. Condition cause financial problems	**.13**	**.19**	.11	—			
5. Condition cause stop working	.08	**.32**	**.32**	**.37**	—		
6. Condition cause decrease work hours	**.35**	**.41**	**.31**	**.28**	**.43**	—	
7. Condition cause avoid changing job	**.19**	**.22**	**.15**	**.19**	**.33**	**.31**	—

All values in bold print are significant ($p < .05$).

Table 4. Correlation matrix for CFA of insistence on sameness latent variable for those with poor communication skills.

Observed Variable	1.	2.	3.	4.	5.	6.
1. Rigid or inflexible behavior	—					
2. Difficulty with change	**.52**	—				
3. Thinks of talks about the same things	**.19**	.12	—			
4. Can't get mind off something	**.33**	**.39**	**.62**	—		
5. Narrow range of interests	**.21**	**.33**	.13	.05	—	
6. Inflexible, hard time changing mind	**.50**	**.60**	**.21**	**.45**	**.30**	—

All values in bold print are significant ($p < .05$).

Table 5. Correlation matrix for CFA of insistence on sameness latent variable for those with good communication skills.

Observed Variable	1.	2.	3.	4.	5.	6.
1. Rigid or inflexible behavior	—					
2. Difficulty with change	**.49**	—				
3. Thinks of talks about the same things	**.40**	**.36**	—			
4. Can't get mind off something	**.36**	**.48**	**.57**	—		
5. Narrow range of interests	**.32**	**.32**	**.44**	**.29**	—	
6. Inflexible, hard time changing mind	**.35**	**.60**	**.31**	**.47**	**.39**	—

All values in bold print are significant ($p < .05$).

Table 6. Correlation matrix for CFA of family burden latent variable for those with poor communication skills.

Observed Variable	1.	2.	3.	4.	5.	6.	7.
1. Money spent on care	—						
2. Hours/week spent providing care	**.35**	—					
3. Hours/week coordinating care	**.28**	**.61**	—				
4. Condition cause financial problems	**.23**	**.21**	.08	—			
5. Condition cause stop working	**.18**	**.33**	**.34**	**.41**	—		
6. Condition cause decrease work hours	**.35**	**.41**	**.29**	**.33**	**.46**	—	
7. Condition cause avoid changing job	.14	**.16**	.11	**.23**	**.42**	**.43**	—

All values in bold print are significant ($p < .05$).

Table 7. Correlation matrix for CFA of family burden latent variable for those with good communication skills.

Observed Variable	1.	2.	3.	4.	5.	6.	7.
1. Money spent on care	—						
2. Hours/week spent providing care	**.43**	—					
3. Hours/week coordinating care	**.35**	**.68**	—				
4. Condition cause financial problems	.03	**.26**	**.21**	—			
5. Condition cause stop working	-.11	**.22**	**.22**	**.34**	—		
6. Condition cause decrease work hours	**.33**	**.36**	**.29**	**.26**	**.33**	—	
7. Condition cause avoid changing job	**.25**	**.31**	**.20**	.15	.10	.03	—

All values in bold print are significant ($p < .05$).

Figure 1. *Model 1. The relationship between insistence on sameness, behavior outbursts, anxiety, and individual QOL.*

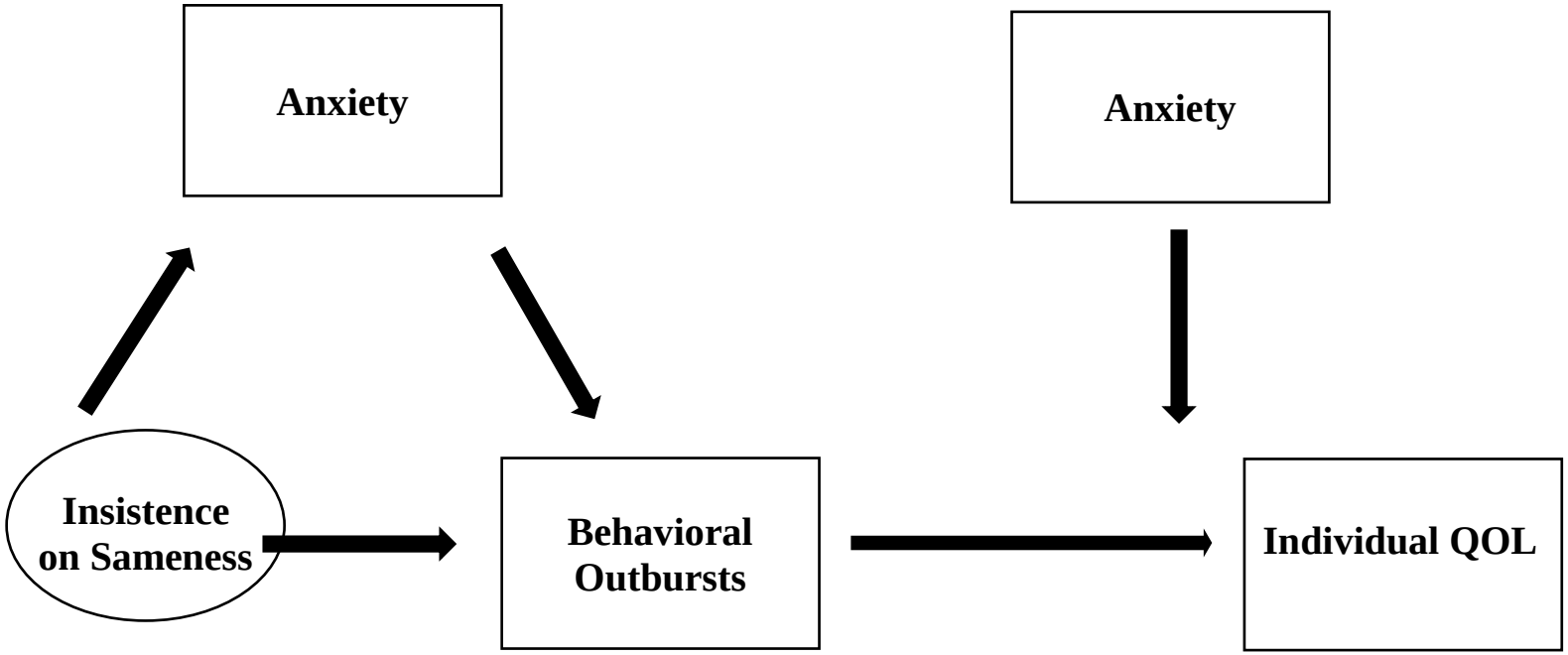


Figure 2. *Model 2. The relationship between insistence on sameness, behavior outbursts, anxiety, and family burden.*

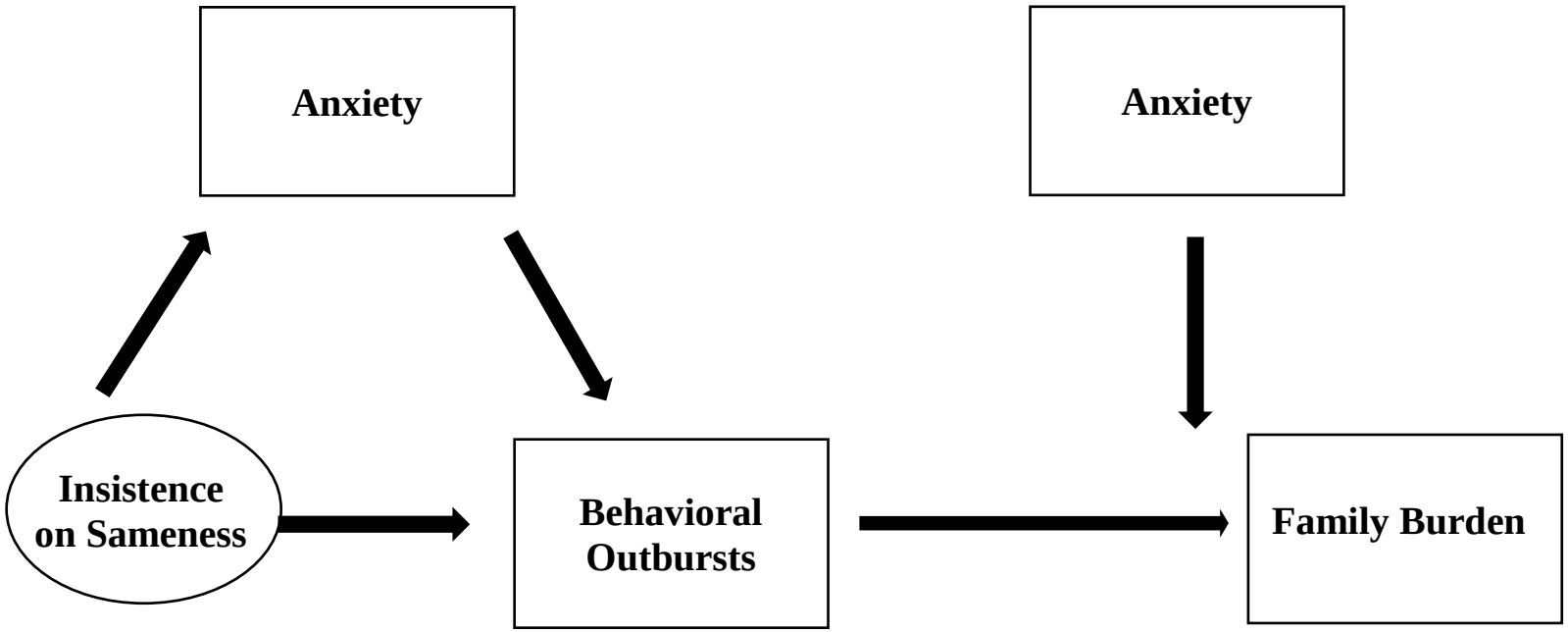


Figure 3. *Sample ascertainment chart.*

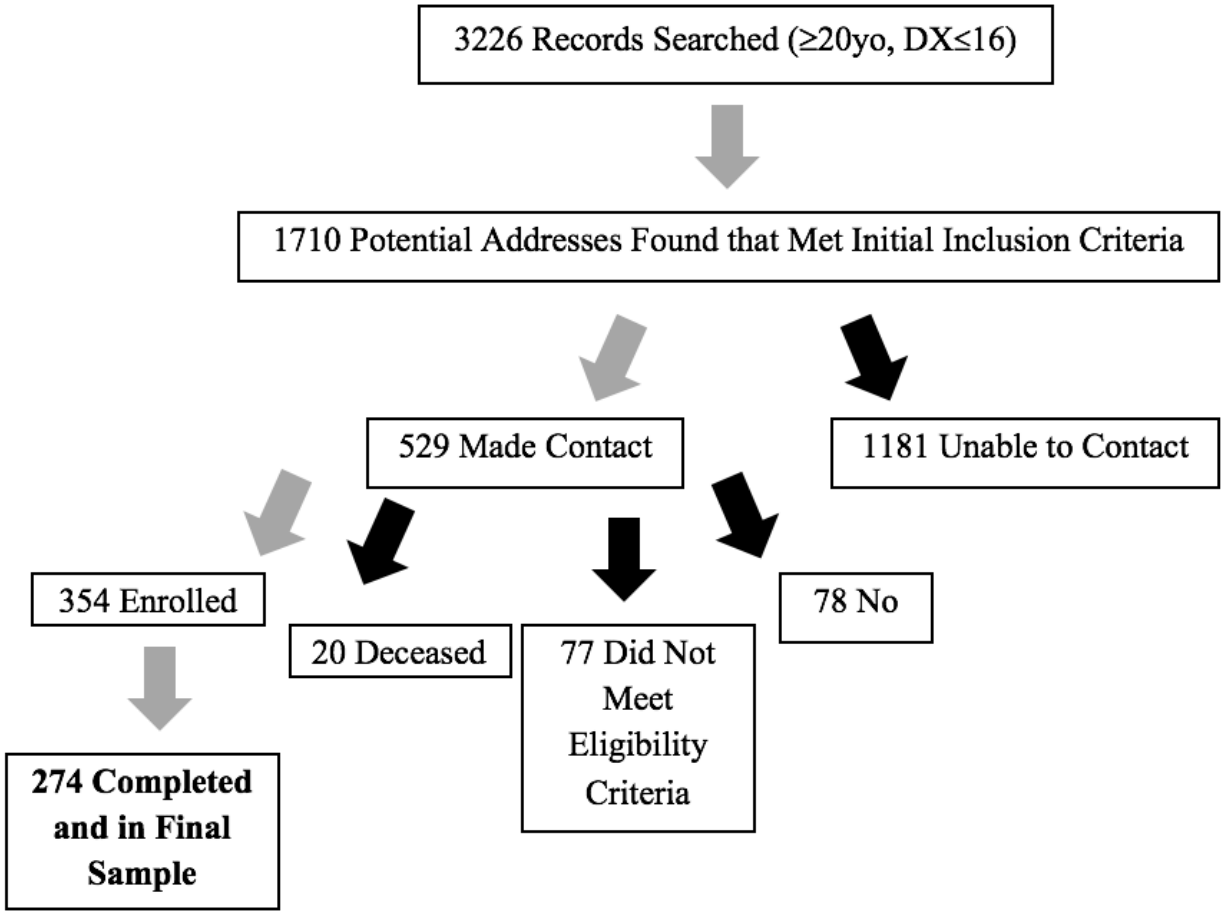


Figure 4. *Insistence on sameness latent variable.*

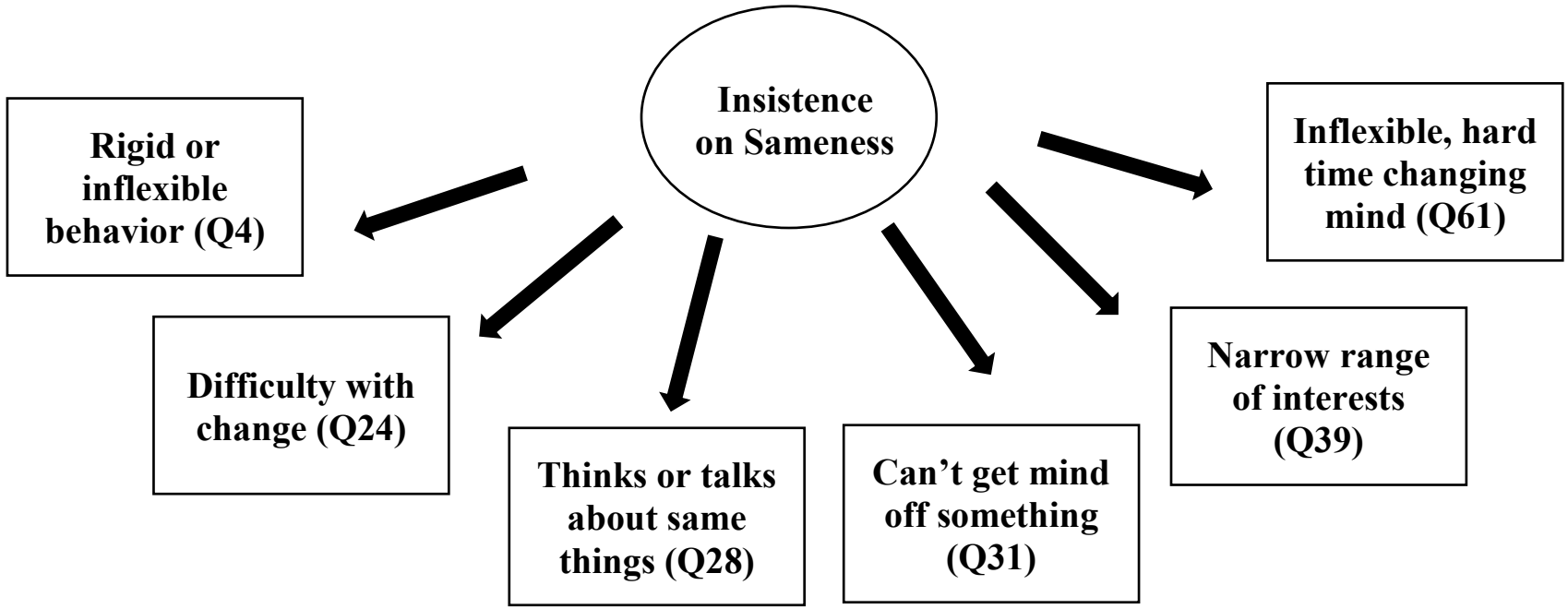


Figure 5. *Family Burden latent variable.*

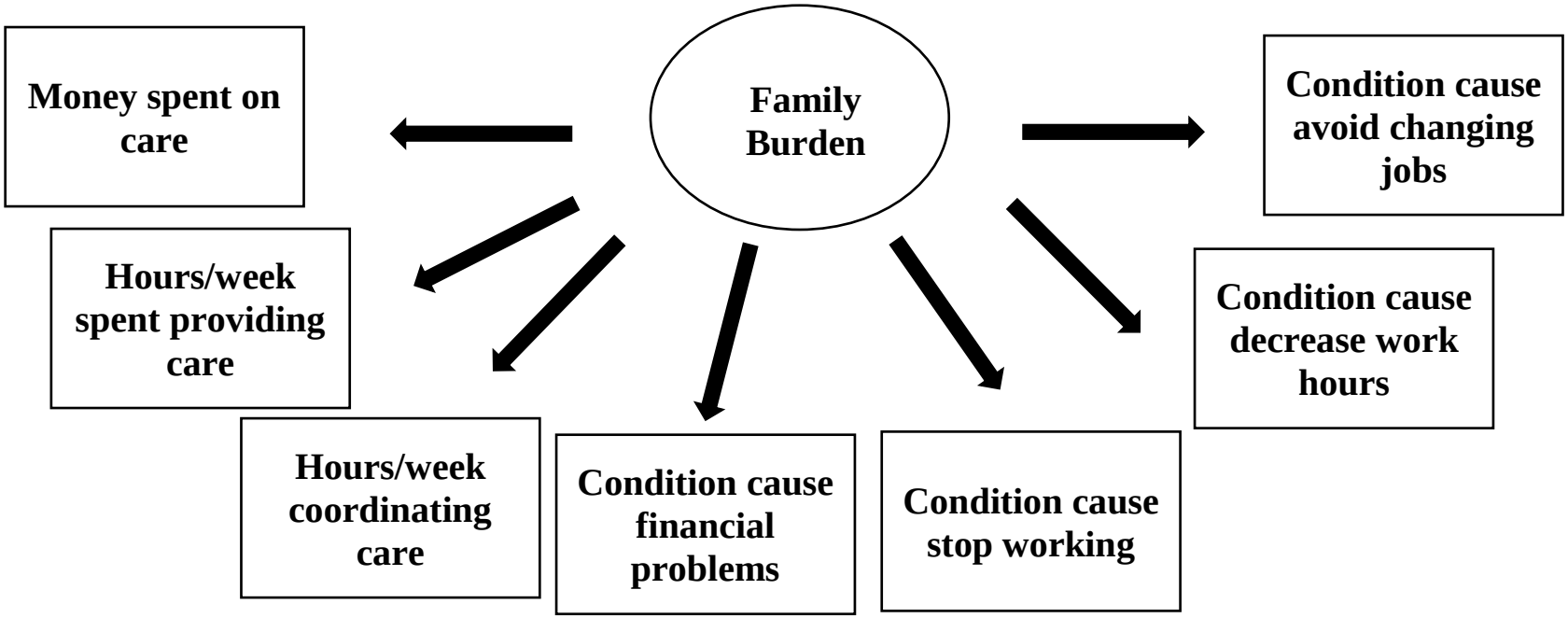


Figure 6. *The relationship between age and QOL Total Raw Score*.

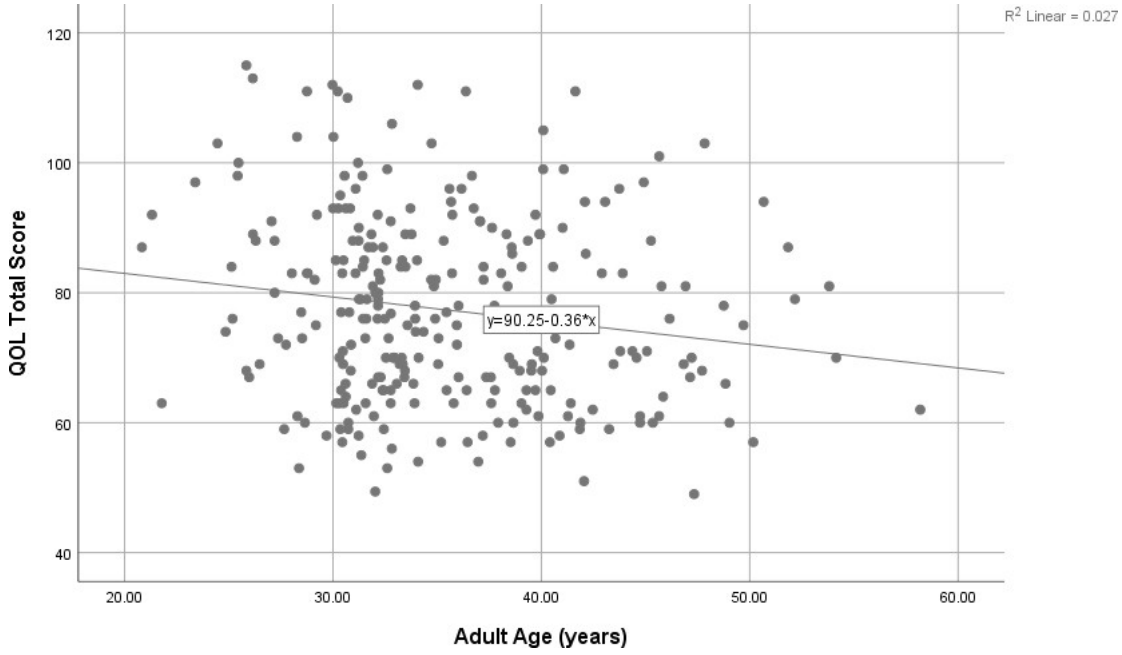


Figure 7. *The relationship between age and Insistence on Sameness Total Raw Score.*

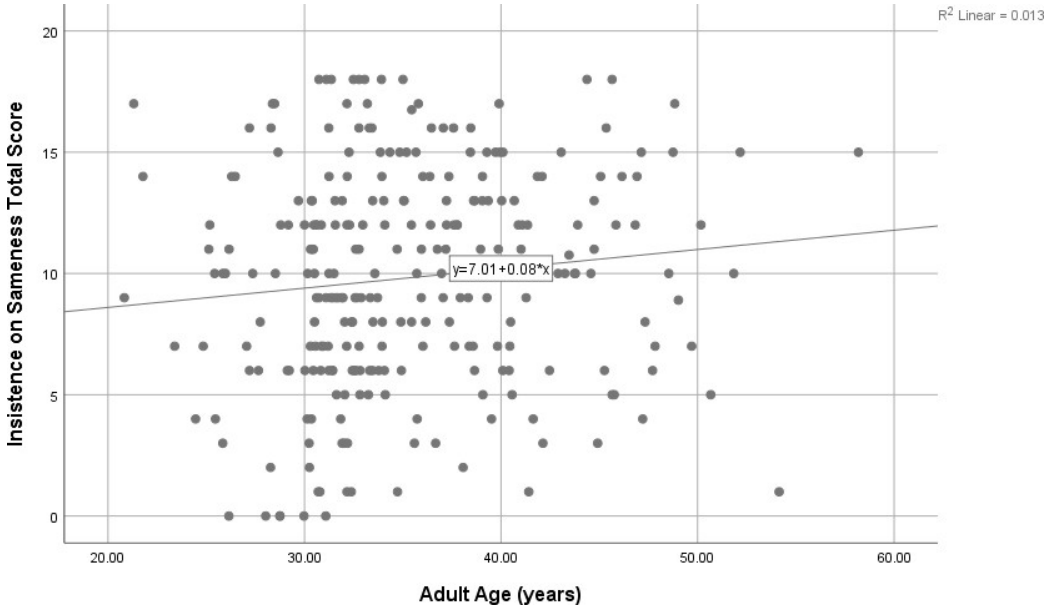


Figure 8. *Finalized Insistence on sameness latent variable.*

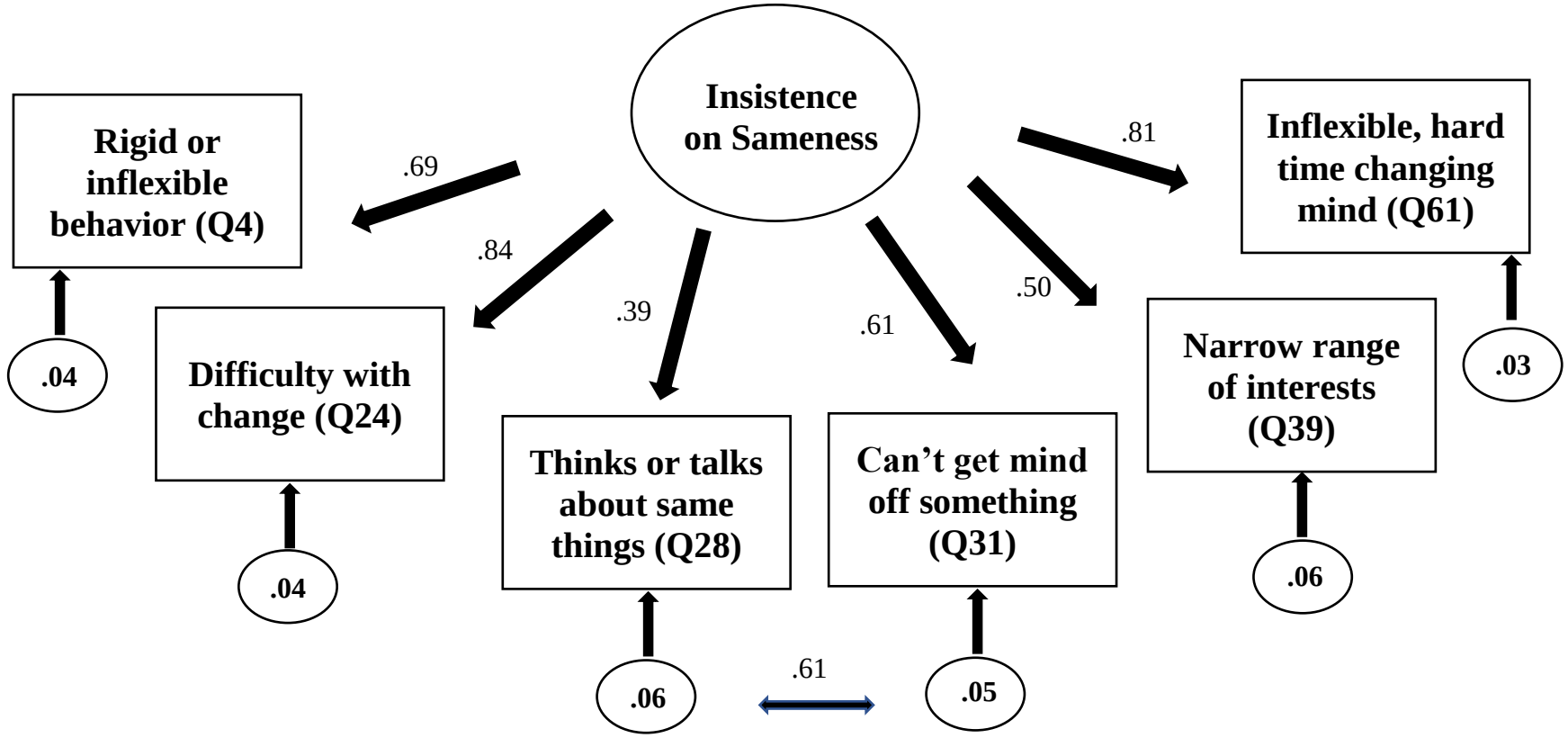


Figure 9. *Finalized Family Burden latent variable.*

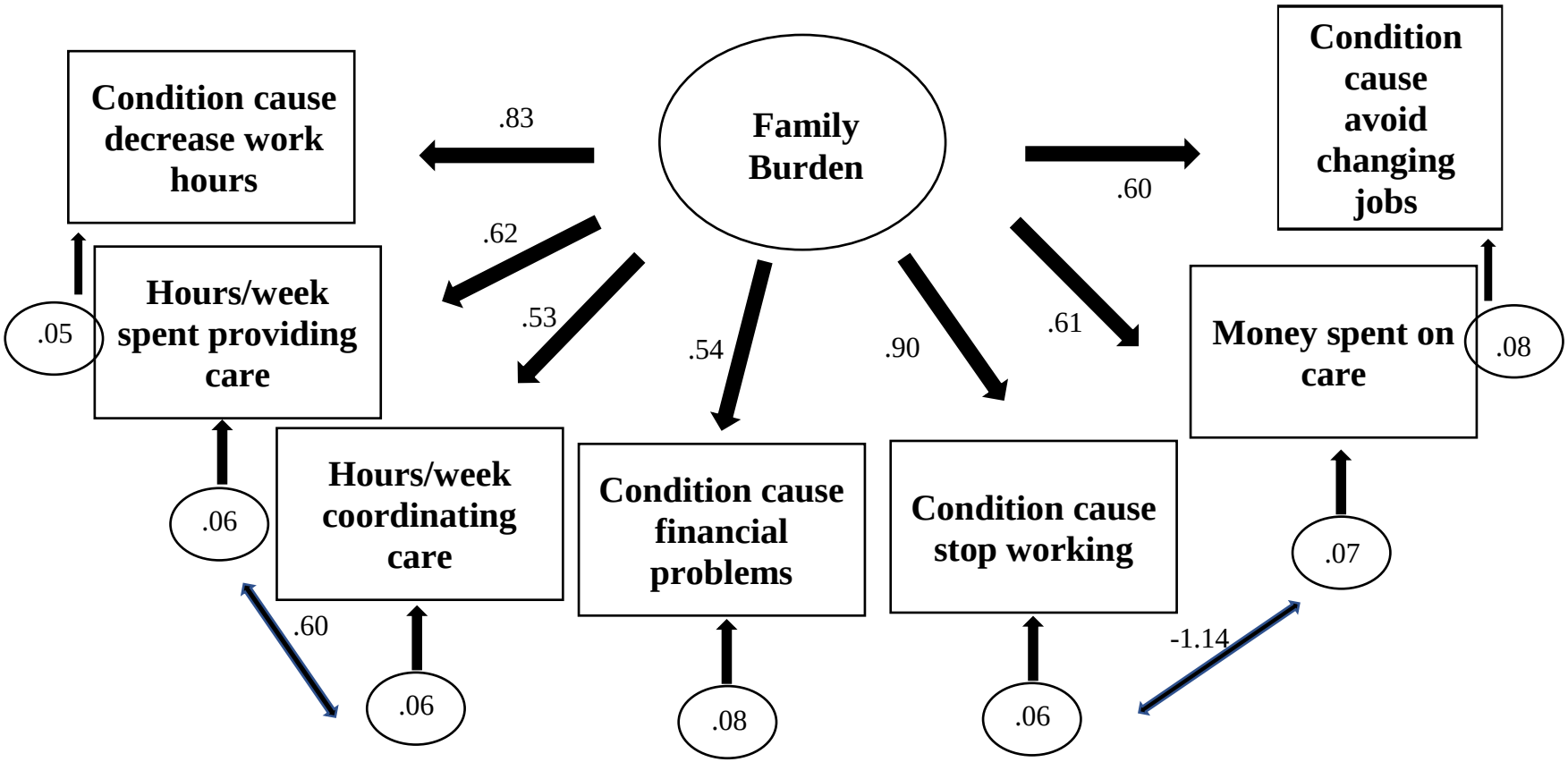


Figure 10. *Finalized Model 1*.

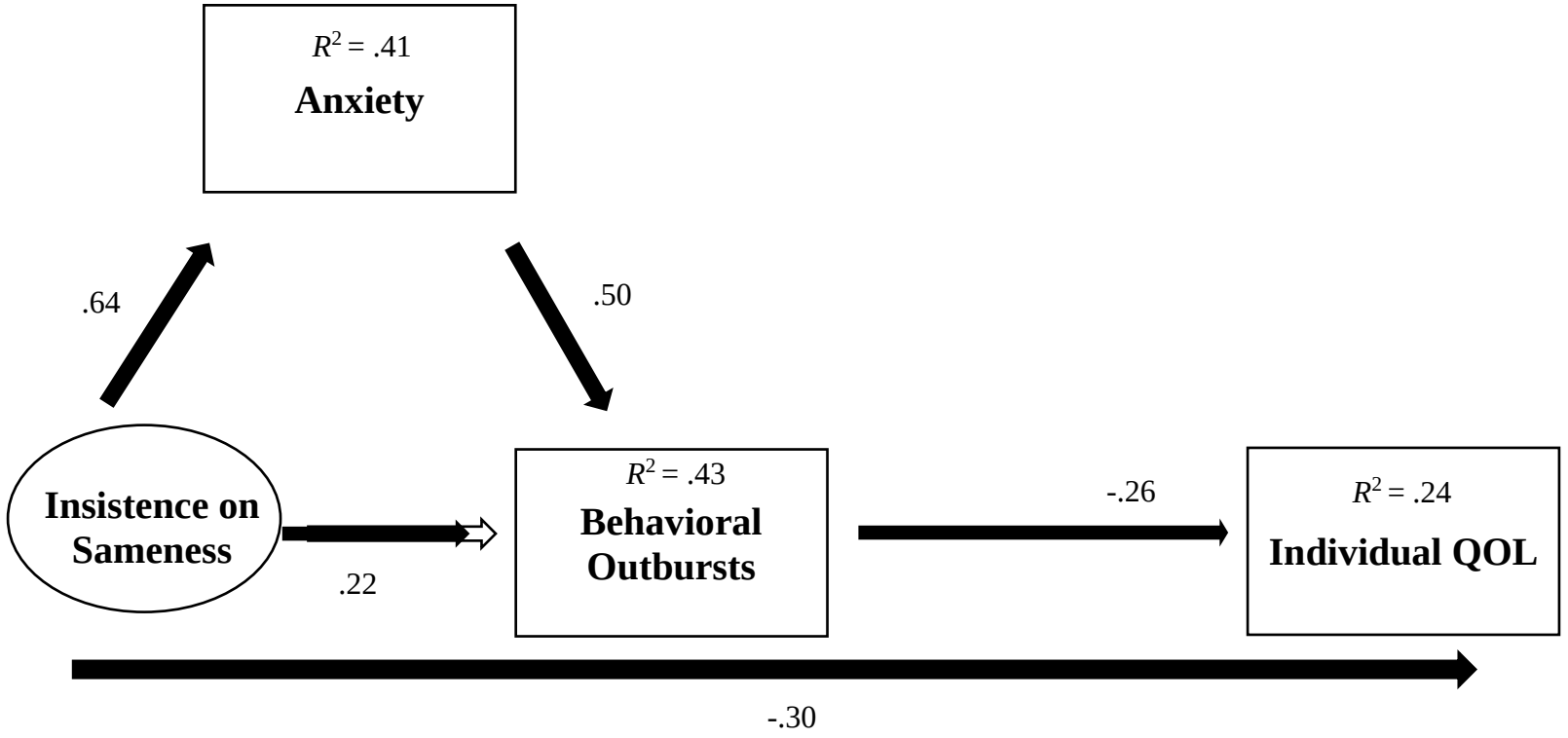
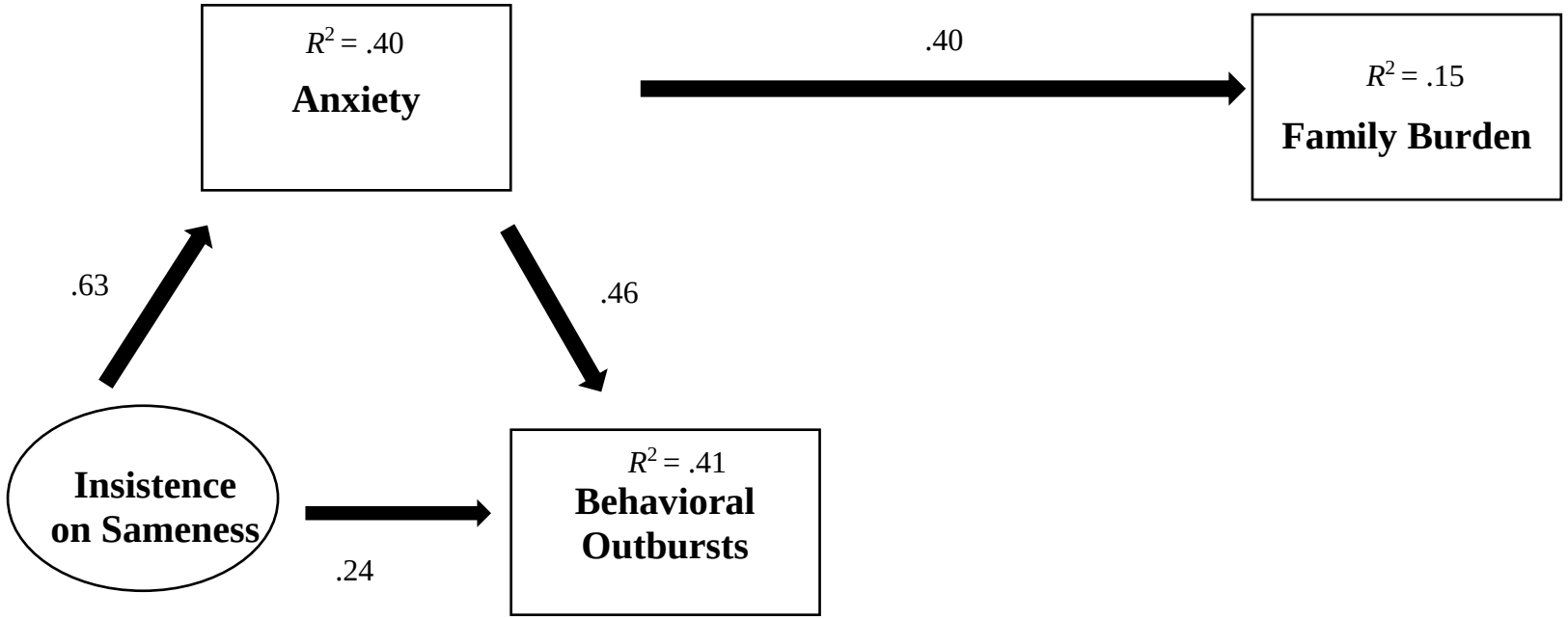


Figure 11. *Finalized Model 2.*



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